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Department for Work and Pensions

Research Report No 350

# Routes onto incapacity benefits: Findings from qualitative research

Roy Sainsbury and Jacqueline Davidson

A report of research carried out by the Social Policy Research Unit on behalf of the Department for Work and Pensions

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# List of abbreviations

CPN	Community psychiatric nurse
DDA	Disability Discrimination Act
DWP	Department for Work and Pensions
HSC	Health and Safety Commission
IB	Incapacity Benefit
IS	Income Support
JRRP	Job Retention and Rehabilitation Pilot
JSA	Jobseeker's Allowance
NDDP	New Deal for Disabled People
NVQ	National Vocational Qualification
SDA	Severe Disability Allowance
SPRU	Social Policy Research Unit
SSP	Statutory Sick Pay
WFI	Work Focused Interview



# Summary

## Chapter 1: Introduction

This report presents findings from a qualitative research project to investigate the routes by which people become recipients of incapacity benefits.<sup>1</sup> The study was aimed at increasing our understanding of how people become Incapacity Benefit recipients so that further policy development can take place around more 'preventive' job retention and rehabilitation measures. Although producing standalone findings that can inform policy thinking, it is also the first stage in a two part project, the second part of which is a large quantitative survey of new Incapacity Benefit claimants to be conducted in 2006.

Chapter 1 highlights the rationale for the study and outlines the major aims and research questions, and outlines the qualitative methods used in the study:

- in-depth face-to-face interviews with 60 new claimants of incapacity benefits;
- follow-up telephone interviews with 54 of the original sample six to seven months later.

The sample comprised people who had made recent claims for Incapacity Benefit and was constructed in order to capture a range of relevant characteristics and circumstances (including gender, health conditions, and educational backgrounds). Full details of the characteristics of the final sample are in Appendix A.

One of the aims of the study was to identify whether there are important 'transition points' on the route to Incapacity Benefit at which policy interventions might be possible. A framework for analysis was developed, derived partly from previous research on incapacity and sickness and also from early fieldwork. The framework comprised sequential phases between transition points in order to capture the diversity of routes onto incapacity benefits presented in later chapters.

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<sup>1</sup> 'Incapacity benefits' include not only Incapacity Benefit itself, but also Income Support (IS) with disability premium, and National Insurance 'credit only' cases.

## Chapter 2: Routes onto incapacity benefits: a review of the literature

As context for the study of people's routes onto Incapacity Benefits, a literature search was conducted to draw together existing knowledge. There is a wide body of literature concerning growth in incapacity-related benefits over the past 25 years or so but less attention has been paid to the factors that contribute to an initial claim.

In this chapter we highlight and discuss some of the salient factors which might contribute to an individual making a claim for Incapacity Benefit, including labour market position, health, relations with employers, interactions with GPs and other health professionals, family and friends, and staff of Jobcentre Plus offices. Literature informing how people leave Incapacity Benefit is relevant to the second stage of the research design, the follow-up interviews (reported in Chapter 6). This is briefly reviewed in the final section of the chapter concentrating specifically on people's expectations and aspirations around moving to work, and on the barriers they might face.

The literature suggests that in understanding moves on and off Incapacity Benefit, it is important to situate people in their social context in terms of their labour market opportunities, health conditions, and access to healthcare and wider social networks.

## Chapter 3: Moving from work to Incapacity Benefit

Two sub-groups were identified within the people in the sample whose route to Incapacity Benefit was preceded by a period in work: people who have had (a) a gradual or (b) a sudden change in their health status. These sub-groups highlight differences between people who had some warning or knowledge of their (often deteriorating) health condition and those whose illness or condition was more sudden in nature and caused them to go off sick or leave work abruptly.

Everyone who experienced a gradual health change had had some contact with their GP or other health professional prior to going off sick, but for some, the contact was limited to an initial meeting with a GP at which they were given an initial sickness certificate but having no direct, face-to-face contact after that. On the whole, the periods of deteriorating health before going off sick were characterised by GPs mainly being concerned with immediate treatment or making referrals for tests and investigations, rather than discussions about work.

Many people with gradual health changes experienced a period of 'struggling on' at work before going off sick. Their experiences in the period were very varied: Some did not tell their employer about their health conditions but received help from colleagues to do their job. Others did tell their employers and were treated sympathetically. There were examples of attempts to adjust work roles or hours of work and of input from occupational health departments. Others had less positive experiences where employers were uncooperative. For some the period of 'struggling on', therefore, ended in their employment being terminated.

People had very varied experiences of the period of being off sick from work and in receipt of Occupational Sick Pay or Statutory Sick Pay up to the point of making a claim for Incapacity Benefit, whether they had experienced a gradual or a sudden change in health. For some, the period was relatively lengthy during which time they had contact with health services, employers and others, such as Jobcentre Plus staff. However for others this period was very short. The length of the period was often determined by sick pay arrangements and sickness management procedures, and by the responses of employers. Where employers kept in contact with employees to find out how they were, employees often took this as a sign that they were valued in their job. Some people reported positive input from occupational health staff but for others there was a (sometimes strong) perception that occupational health staff were ultimately on the 'side' of the employer. GPs rarely raised the topic of work, but some employees did and reported being met with supportive responses. Work was not discussed with other health professionals.

There was little evidence of either family and friends or staff of Jobcentre Plus offices having much impact on decisions to claim Incapacity Benefit.

People's likelihood of experiencing a period off sick was linked to their labour market position. People in low paid, low status insecure employment with little or no occupational benefits contrasted with those with more stable employment enjoying (differing degrees of) employment rights and benefits.

## Chapter 4: Moving from non-work to Incapacity Benefit

Chapter 4 is the first of two chapters which deals with those people who flow onto Incapacity Benefit from a 'non-work' status. There was a great deal of heterogeneity in this group in terms of attachment to the labour market and stage in the life course. It was clear, however, that health, whether conditions were relatively new, longstanding or fluctuating, was a key factor in all of the claims and that this interacted with the circumstances in which people found themselves in relation to paid work. Other people were at particular stages in life where securing paid work was not their only or primary concern, for example, those with very young children or those who wanted to retire.

Some claims in this route were associated with the structure of the wider social security system and in particular the qualifying periods for National Insurance contributions needed to be eligible for benefit. Some people had effectively undergone a 'waiting period' for Incapacity Benefit.

Many of this sub-sample were not on any kind of social security benefit prior to claiming Incapacity Benefit but had other types of 'non-work' status and were, therefore, not in contact with any statutory benefit or employment agencies prior to becoming unwell.

Some people had the experience of GPs acting *responsively* to their changing health either offering sickness certificates, or more *proactively*, by suggesting and

encouraging a claim for Incapacity Benefit (in this study this occurred when the person had also discussed wider problems with their GP, especially financial problems). Other people made the initial request for a certificate, which their GP then supplied. There was evidence of Jobcentre Plus staff advising existing recipients of Jobseeker's Allowance (JSA) who report to them that they are not available for work due to ill-health that they should seek a sickness certificate from their GP.

In some ways there is evidence in this chapter of health and benefit services working in a joined up way. A picture emerges in the accounts of some people in the study of well-established processes being set in motion when someone presents themselves as unwell either to their GP or to someone from Jobcentre Plus. As one research participant put it *'I just went with the flow basically'*.

## Chapter 5: Moving from work to 'non-work' to Incapacity Benefit

This chapter deals with people who have had a more complex route to Incapacity Benefit rather than a clearly identified path from either work or 'non-work'. Like Chapter 4 it deals with people who flow onto Incapacity Benefit from a 'non-work' category but who had (relatively speaking) recently also been in work. Two sub-groups are identified in the chapter. The first sub-group concerns those people who had left their job (for example, because of having being made redundant) and had subsequently become ill. The second sub-group of people, conversely, had become ill and then lost their job. At the extreme, this sub-group illustrates that some people's trajectory onto Incapacity Benefit is characterised by time spent moving between lower service sector work, ill-health and benefits.

Those in the 'work, non-work, Incapacity Benefit' group share similarities with those in Chapters 3 and 4. On the one hand they have recently been in work (like those people in Chapter 3) and on the other they have had some other status previous to their Incapacity Benefit claim. Unlike some of those in Chapter 3, however, those in this group had no opportunity of occupational sick pay, or of retaining their employment because they had either already lost it when they became ill or they subsequently lost their employment upon becoming ill.

Although the sub-group of people who had lost their jobs as a result of being unwell was very small, it was noticeable that the three people who had mental health conditions all worked for small employers, and although there had been some efforts to accommodate reduced capabilities, these had not prevented the job ending.

No one in this small group left their employment on the advice of their GP. Rather it seems that GPs were contributory to people staying in work for as long as they did. Some of the people at this stage did not know the full nature or extent of their conditions. Others had managed their condition for some time previously. The contact that people had with Jobcentre Plus staff in this group was principally to

process their benefit claim. None said that the staff had had an influential role in the decision to claim Incapacity Benefit.

There was therefore no evidence among this sub-group that people were in any sense 'pushed' towards Incapacity Benefit by health professionals, family and friends or Jobcentre Plus staff. Rather, Jobcentre Plus staff acted more in what could be termed a 'claimant-centred' way by providing people with advice about what benefits might be appropriate for them when they become sick.

## Chapter 6: Routes off Incapacity Benefit

This chapter reports findings on the labour market position of the sample six or seven months after the initial research interview. It was possible to recontact 54 people from the original sample of 60. Their benefit and employment statuses fell into four main groups: in paid employment and no longer receiving Incapacity Benefit (11); not in receipt of Incapacity Benefit, nor in work (7); in a new period of claiming Incapacity Benefit (6); and in the same period of benefit receipt (30).

Seven people had returned to their old employer, two had started new jobs and two had begun self-employed work. There was a wide range of types of employment, including professional, skilled and manual jobs. All but one of the 11 people in work had taken on full-time jobs; none had come from the 'non-work' to Incapacity Benefit route. Most people who had returned to work mentioned improvements in their health (often the result of treatments received) or input from their GP as important factors in their return to work. No one said contact with Jobcentre Plus staff was a factor.

People who had left Incapacity Benefit but were not in work were either on JSA or IS, or had other sources of income and were not in receipt of any social security benefits. Most of these viewed their situation positively; four of the seven people here wanted to work and three thought they would be in work within the following three months.

A small number of people had been employed between the two research interviews but were not at the time of the follow-up interview. They all cited changes in their health as important factors in both being able to take on work and, subsequently, for their jobs ending. This group, though small, did seem to be characterised by their employment being at the lower, insecure end of the labour market.

Thirty people had remained on Incapacity Benefit for the duration of the research study. Only five said their health had improved, although of these, three said that the improvement was not enough for them to consider working. In contrast, nearly half reported that their health had worsened and nearly as many reported no change. One of the most striking findings from this group was the change in thoughts about working between the two research interviews. In the first interview the large majority expressed positive aspirations about working in the future, but at the second interview only a few were confident of returning to work in the short- to medium-term, with most people citing health as the main barrier.



In conclusion, many of the people who returned to work and were still in work at the follow-up interview appeared to have benefited from the combination of improved or stabilised health conditions, a strong commitment to work and one or more other favourable factors such as having a job to return to or transferable skills.

## Chapter 7: Summary and conclusion

This chapter summarises the main findings from the study by revisiting the research questions that informed the project, and discusses implications for policy. Some data are also presented on attitudes to Incapacity Benefit and tax credits.

People's attitudes fell into one of three categories: One set of views was largely negative with the receipt of Incapacity Benefit being associated with stigma and feelings of being degraded. In contrast others viewed Incapacity Benefit more as either a right or entitlement, or as a means of financial assistance in times of need. There was no apparent link between people's views about Incapacity Benefit and whether or not they came off benefit. The data on people's attitudes and use of tax credits was very limited in this study. Only a minority had even the smallest understanding of tax credits and even fewer had used them. At the time of the follow-up interviews, not one of the study group was getting tax credits.

The issue of health dominated most people's accounts of their route on and either their route off or their continued receipt of Incapacity Benefit. The following questions therefore arise for policy: (a) can the onset or deterioration of health problems be avoided, (b) if they cannot, what can be done to prevent health conditions leading to a period of sickness, and (c) what can be done when people are off sick to avoid the need to claim Incapacity Benefit?

Current government initiatives are, to an extent, addressing these. The potential for more employer involvement and for occupational health services is suggested by the findings from this study. Healthy working practices and safe and healthy environments could act as very early preventive measures that might halt a route onto Incapacity Benefit. Proposals for an increase in occupational health services for employers can, therefore, be seen as a helpful policy response here.

Many people in this study spent time on health service waiting lists for consultations, investigations and treatment. Clearly for them, access to speedy and appropriate health interventions had the obvious potential to help them hopefully return to work before a claim to Incapacity Benefit becomes necessary. Any possibilities for preventing people who have a 'non-work' status from eventually moving on to Incapacity Benefit would appear to be very restricted and limited to health care that might, for some, maintain them as job seekers.

The finding that the aspirations and expectations about work of many of the people still on Incapacity Benefit at the second research interview had changed (with fewer people expecting to work again in the medium-term), suggests that more effective policy interventions in the earlier months of a claim would be useful.

Any measure or arrangements that help maintain contact between employer and employee would be valuable. Included here might be formal sickness management policies and procedures (properly implemented) and, again, access to occupational health services.

The study did not generate suggestions, either from analysis of the data, or from the research participants themselves, about how a greater preventive role could be played by GPs or by Jobcentre Plus staff.

The findings will have relevance for forthcoming policy debates around the reform of Incapacity Benefit. There is an opportunity here to remove some of the aspects of the benefit that appear to militate against people's strong desire to work.

This study will inform the development of a large quantitative survey of new Incapacity Benefit recipients planned for later in 2006. Many of the findings have been necessarily tentative or raised as hypotheses, therefore. However, the opportunity to pursue them further should generate findings that are generalisable to the wider Incapacity Benefit population and which can further inform policy.



# 1 Introduction

This report presents findings from a qualitative research project to investigate the routes by which people become recipients of incapacity benefits.<sup>2</sup> The study was commissioned by the Department for Work and Pensions (DWP) and carried out by the Social Policy Research Unit at the University of York in 2005.

There has been much policy activity since 1997 aimed at helping people who are on long-term sickness and disability benefits move towards and into work. This includes the New Deal for Disabled People, the Incapacity Benefit ('Pathways to Work') pilots, and policies to make work pay (including the minimum wage, tax credits and incentives within Incapacity Benefit). There has also been policy innovation, in the Job Retention and Rehabilitation Pilot, to keep people who are on sickness absence leave in contact with the labour market so that a move to Incapacity Benefit becomes unnecessary.

However, very little is known about how people become recipients of Incapacity Benefits, though some insights can be gained from official DWP administrative data. For example, it is known that a large proportion of Incapacity Benefit recipients are previously unemployed or economically inactive rather than coming to Incapacity Benefit from employment, and that the most common health condition recorded for recipients is a mental health problem.<sup>3</sup> However, we do not know from official statistics what people's circumstances were in the period leading up to claiming, whether and how their employment and benefit histories influence the decision to claim, and the roles played by key actors such as employers, health professionals, Jobcentre Plus staff and family and friends.

This qualitative study was aimed at increasing our understanding of how people become Incapacity Benefit recipients so that further policy development can take

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<sup>2</sup> 'Incapacity Benefits' include not only Incapacity Benefit itself, but also Income Support with disability premium, and National Insurance credits.

<sup>3</sup> DWP internal document Incapacity Benefit payment claimants versus Incapacity Benefit credits only claimants, December 2003.

place around more 'preventive' job retention and rehabilitation measures. The study is not only intended to produce standalone findings that can inform policy thinking, it also is intended to serve as the first stage in a two stage project, the second stage of which is a large quantitative survey of new Incapacity Benefit claimants to be conducted in 2006.

This introductory chapter will describe the aims and objectives of the study and set out the research questions to be addressed (Section 1.1). This is followed (Section 1.2) by a brief description of the research design and methods (with a fuller description appearing in Appendix A). Section 1.3 presents an analytical framework that we use in subsequent chapters to explore the different stages that people might go through on their route to Incapacity Benefit. Section 1.4 describes briefly the structure of the report.

## 1.1 Aims and objectives of the study

The aims of the study can be summarised as follows:

- To provide a detailed investigation of the routes and processes by which people leave work or benefits and flow onto Incapacity Benefit (including people economically active but not in work, economically inactive, and people in paid employment).
- Identify any 'transition points' at which current or future interventions may help people into work or active job seeking.
- Provide greater understanding of the perceptions people have about qualifying for and receiving Incapacity Benefit.
- Increase understanding of experiences of, and attitudes to, the disability element of tax credits.
- To investigate people's exits from Incapacity Benefit in relation to their routes on to the benefit.
- Provide recommendations for the planned large-scale survey of Incapacity Benefit recipients.

Within these broad aims the research aimed to cover the following topics:

*Reasons for claiming:* including people's perceptions of Incapacity Benefit; the extent to which they have choices in the process of claiming; experiences of job retention responses; experiences of moving from other benefits onto Incapacity Benefit.

*Health and capability changes:* including how people experience changes in health and capability that precede a claim; how they view what they can and cannot do, particularly in relation to work.

*Roles of other key actors:* including employers, GPs, hospital doctors and other health professionals, family and friends and Jobcentre Plus staff.

*Expectations and aspirations:* including people's attachment to the labour market and their feelings about work, knowledge and attitudes towards financial incentives to work.

*Experiences of coming off Incapacity Benefit:* including how and when people come off Incapacity Benefit, the relationship between people's routes to Incapacity Benefit and their routes off.

## 1.2 Research design and methods

This section summarises the research design and methods for the qualitative study of people's route to Incapacity Benefit. (A fuller description of methods is in Appendix A.)

Qualitative methods are well-suited to exploring the perceptions, beliefs and attitudes that contribute to people's decision making and behaviour. The findings that emerge from qualitative methods are not statistically representative and cannot be generalised to the wider population. Rather they seek to understand and describe processes, and clarify and explain the sometimes complex interaction of influences and forces that shape behaviour.

The qualitative study comprised:

- in-depth face-to-face interviews with 60 new Incapacity Benefit claimants;
- follow-up interviews by telephone six to seven months later.

### 1.2.1 The study sample

The sampling frame was provided by DWP and comprised people who had made recent claims for Incapacity Benefit. The sample for the study was constructed to achieve diversity of relevant characteristics and circumstances. The main aim was to include men and women who had a range of ages and health conditions. We also aimed to achieve diversity in household circumstances, economic circumstances, educational backgrounds and benefit histories. Full details of the characteristics of the final sample are in Appendix A. The distribution of men and women, ages and main health conditions is presented in Table 1.1.

**Table 1.1 Main characteristics of the achieved sample**

	Number
<b>Sex</b>	
Men	35
Women	25
<b>Age</b>	
18-29	10
30-49	23
50 and over	27
<b>Main type of health condition</b>	
Mental health	13
Cardiovascular	10
Musculoskeletal	23
Other <sup>1</sup>	12
Unknown	2

<sup>1</sup> Other health conditions included sensory impairment, respiratory diseases, conditions of the digestive system, diabetes, multiple sclerosis and pregnancy.

The fieldwork sites were based in Jobcentre Plus districts and chosen to represent different rates of Incapacity Benefit reciprocity using administrative data supplied by DWP. Two sites were selected with a 'low' rate of Incapacity Benefit claims (around three to four per cent of the working age population) in order to generate a sufficient sample size; two sites with an 'average' Incapacity Benefit rate (six to eight per cent); and one site with a 'high' rate (over ten per cent). Twenty interviews were carried out for each category of district.

### **1.2.2 Initial face-to-face interviews**

The initial interviews were carried out in the research respondents' homes and most were tape recorded and transcribed for analysis. The interviews were conducted using a topic guide (see Appendix B) that covered:

- household circumstances and work history;
- circumstances leading to their claim (including health, financial situation, role of employers, GPs/medical professionals, family/friends, Jobcentre Plus staff);
- perceived transition points;
- perception of Incapacity Benefit;
- expectations and aspirations for the future.

The interviews took place in March and April 2005 with people who had claimed Incapacity Benefit in November/December 2004.

### 1.2.3 Follow-up interviews

The aim of the follow-up interviews was to gather data on people's labour market position six to seven months after the initial interview. It was hoped that some insight might be gained into whether their route **on** to benefit had any influence on exits.

Of the 60 people in the original sample, follow-up interviews were carried out with 54. Six people could not be contacted and did not respond to telephone calls and letters. Data were collected using a questionnaire (reproduced in Appendix C).

Administrative statistics show that around a quarter of all new claimants leave Incapacity Benefit within six months of claiming and over a half leave within a year. There was an expectation, therefore, that perhaps between a third and a half of the original sample of 60 for this study would have left Incapacity Benefit by the time of the second interview. In summary, the labour market position of the 54 people successfully followed up were within expectations as follows:

- 11 people not on Incapacity Benefit, in paid employment;
- seven not on Incapacity Benefit, but not in work;
- 30 still claiming Incapacity Benefit;
- six on a new period of claiming Incapacity Benefit.

Full analysis of the data from the follow-up interviews is presented in Chapter 6.

## 1.3 An analytical framework for understanding routes onto Incapacity Benefit

One of the aims of the study was to identify whether there are 'transition points' on the route to Incapacity Benefit at which policy interventions might be possible. In the following chapters we analyse routes in terms of the following 'phases' that people might experience. These phases are partly derived from previous research on incapacity and sickness and also informed by early fieldwork. The phases are constructed sequentially and so capture the diversity of routes onto Incapacity Benefits.<sup>4</sup>

### 1.3.1 Phase 1 – Initial health/capability change (the 'warning signs' phase)

During this phase a person's health condition changes in a way that has relevance for how they are able to do their job. This might be because of a deterioration of an existing condition or the onset of a new condition. People may experience some effects on their capabilities at home or in work, but they do not experience any major

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<sup>4</sup> As will become clear in later chapters, not all people experience all possible phases on the route to incapacity benefits.



problems at work. In other words they are able to carry out the functions of their job regardless of the change in their health. We can call this period the 'warning signs' phase. Many people will at some point return to previous levels of health or adjust to their new health situation. Others, however, may continue to experience health problems and, if they are in work, move to the next phase.

### **1.3.2 Phase 2 – Health change affecting work (the 'struggling on' phase)**

At some point people in employment who had previously been carrying on their required duties at work without any problems will reach a point when their performance is affected. During this period they continue working but have difficulty coping with the demands of the job and begin to struggle. Again, for some people this will be a temporary phase from which they recover and return to fulfilling the requirements of their job. Others may make satisfactory adjustments to their work such as changed hours or duties. However, for some people this period of 'struggling on' precedes the point at which they have to stop work and 'go off sick'. People not in work will not of course experience this or the next phase, but might experience a comparable point at which their daily capabilities or ability to look for work are affected to such a degree that the requirements of, for example, Jobseeker's Allowance (JSA) become impossible to meet.

### **1.3.3 Phase 3 – Sickness absence from work (the 'off sick' phase)**

This period is characterised by being away from the workplace but still in touch with an employer and in receipt of some form of income replacement. This might be payments from an occupational sick pay scheme, or Statutory Sick Pay (SSP). During this period people are not claiming Incapacity Benefit, although some will do when payments from their employer or through SSP come to an end.

### **1.3.4 Phase 4 – On Incapacity Benefit**

The final phase of the route to Incapacity Benefit is receipt of the benefit itself following a successful claim. Some people will still have contact with employers during this phase and some will continue to have contracts of employment. Others, however, will lose or leave their employment at this stage and for them this is a move further away from the labour market.

As will be seen in later chapters we have tried to extract from people's accounts of their route to Incapacity Benefit, their experiences in each of these phases, and in particular tried to explore their thinking and behaviour in relation to moving onto Incapacity Benefit. We will also show how these phases can be useful in thinking about possible policy responses aimed at intervening at some point, either during one of the above phases or at the point of transition between one phase and the next.

## 1.4 Note on terminology

Definitions of disability and impairment differ over time and context. This report primarily refers to people with a health condition because a claim for Incapacity Benefit was mostly made when a specific impairment or health condition appeared or deteriorated. Notwithstanding the report's focus on health conditions, some of the research participants, in line with the social model of disability (which argues that modern social arrangements exclude people with impairments), were disabled.

Reference is made in the report to:

- economically active people, i.e. those in employment and those unemployed;
- economically inactive people, i.e. carers, students, early retirees or long-term sick and disabled people.

## 1.5 Structure of the report

Chapter 2 presents the literature review carried out at the start of the study and identifies some of the salient factors which might contribute to an individual making an Incapacity Benefit claim including the labour market, health, relations with employers, interactions with GPs and other health professionals, family and friends, and staff of Jobcentre Plus offices. As context for the later chapter on routes off Incapacity Benefit the final section of the chapter concentrates specifically on people's expectations and aspirations around the future and moving to work, and on the barriers they might face.

Chapter 3 examines in detail the experiences of the people in the sample whose route to Incapacity Benefit was preceded by an immediate period in work. The chapter covers people's experiences of health changes, distinguishing between **gradual** and **sudden** changes, and of going through the phases identified in Section 1.3 above. Importantly, the roles of key players – employers, health professionals, family and friends and Jobcentre Plus staff – are explored.

Chapter 4 is the first of two chapters that deal with those people who flow onto Incapacity Benefit from various forms of 'non-work' status, including people in receipt of other social security benefits and those without benefit income. The chapter deals with people who have been out of the labour market for a relatively long period (whether economically active as jobseekers or inactive as people in some form of 'retirement') and, like Chapter 3, examines experiences of health changes and the roles of key actors on the route to Incapacity Benefit.

In Chapter 5 we turn to an important but smaller sub-group of people whose claim for Incapacity Benefit was, like the people in Chapter 4, from a 'non-work' status. However, they are distinguished from the earlier group because their route to Incapacity Benefit was more complex and their period of 'non-work' relatively short and came after an episode in employment. Again, the phases they experience and the role of key players are explored.

Chapter 6 presents an analysis of data collected from the follow-up interviews in October 2005. In particular people's routes off Incapacity Benefit (some, but not all, of which were into paid employment) and any links with their route on are explored.

Chapter 7 concludes the study with a summary of the main findings and a consideration of their policy implications in the light of recent policy development in relation to job retention and rehabilitation.

## 2 Routes onto incapacity benefits: a review of the literature

### 2.1 Introduction

As context for the study of people's routes onto Incapacity Benefits, a literature search was conducted to draw together existing knowledge. There is a growing amount of literature about what can contribute to getting people on incapacity benefits back to work but far less attention has been paid to the factors that contribute to an initial claim.

In this chapter we highlight and discuss some of the salient factors which might contribute to an individual making an Incapacity Benefit claim including the labour market, health, relations with employers, interactions with GPs and other health professionals, family and friends, and staff of Jobcentre Plus offices. Literature informing how people leave Incapacity Benefit is relevant to the second stage of the research design, the follow-up interviews (reported in Chapter 6). This is briefly reviewed in the final section of the chapter concentrating specifically on people's expectations and aspirations around moving to work, and on the barriers they might face.

### 2.2 The growing numbers of Incapacity Benefit recipients

Concerned with exploring routes onto Incapacity Benefit, this research is situated in a wider body of work prompted by the growth in incapacity-related benefits over the past 25 years in the UK which is now well documented. In 1979, the total claiming incapacity-related benefits stood at 0.7 million. The figure for 2005 was 2.7 million, far exceeding both claimant and International Labour Organisation unemployment counts and representing over seven per cent of the total UK working age population<sup>5</sup> (Fothergill and Smith, 2005: 11).

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<sup>5</sup> Defined as all 16-64 year old men and all 16-59 year old women.

Several reasons for this growth have been posited. For example, Beatty and Fothergill (1996) and Alcock *et al.* (2003) have consistently argued that the growth in the rise of incapacity benefits is inextricably linked to the process of de-industrialisation in the UK and the loss of jobs in Britain's older industrial areas. The top 30 districts in Great Britain for Incapacity Benefit claimants thus '*reads like a roll call of older industrial Britain*' (North England, Scotland and Wales) (Fothergill and Smith, 2005: 13). The argument runs that in a more favourable local labour market, at least a proportion of those on Incapacity Benefit would be in employment.<sup>6</sup> A further and related argument is that the nature of work has changed over the past 25 years, and some commentators have noted an increasing polarisation in the nature of jobs available in the UK labour market, put simply: well paid ones and low paid ones with few prospects, but fewer 'middling' ones (Goos and Manning, 2003: 70). There are also more part-time and temporary jobs around, with concomitant implications for security of employment, which feature disproportionately in the stock of vacancies (Gregg and Wadsworth, 1999: 4).

It has also been suggested that previous governments actively encouraged a transition to sickness benefits as a way of reducing the numbers on Unemployment Benefit (Adams, 1999; Bivand, 2002) and that, comparatively speaking the higher rate of Incapacity Benefit in relation to unemployment benefit acted as a financial incentive for claimants. Finally, it has been suggested that GPs may have exacerbated the above trend in recognising that, manual workers in particular, would struggle to find employment in areas of high unemployment (Legard *et al.*, 2002; Ritchie *et al.*, 1993).

In an attempt to stem this growth, policy responses over the past decade to incapacity-related benefits have included the introduction of a stricter work test (in 1995) with the change from Invalidity Benefit to Incapacity Benefit, the introduction of the New Deal for Disabled People (NDDP), and the enactment of the Disability Discrimination Act (DDA) although it should be recognised that these had much wider objectives. Other policy innovations such as the introduction of the minimum wage and tax credits have also been relevant in the reduction of the numbers of people on incapacity benefits. Grover and Piggott (2005: 711) explicitly link changes in the benefit system to changes in the labour market, noting, for example, that the change to Incapacity Benefit from Invalidity Benefit can be seen as part of the increasing 'work first' approach – especially the change from 'own occupation' to 'all work' test. The '*loss of permanent employment, particularly in heavy industry and primary production, and the shift to flexible labour markets in light manufacturing and the service sector it is thought (further) opened labour markets to disabled people*'. The authors go on to argue that forecasted demographics and the need to increase the effective labour supply in order to avoid labour shortages and inflationary pressure (Grover and Piggott, 2005: 715) are partly the prompt behind the latest round of policies, which include 'work first' interviews and action plans, the NDDP, increased financial incentives and attempts to address discrimination faced by disabled people via DDA (Grover and Piggott, 2005: 715).

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<sup>6</sup> Authors associated with this argument often take pains to point out that Incapacity Benefit claimants are not claiming fraudulently, but rather that, in previous times there would have been employment that they could do with their ill-health conditions.

## 2.3 Influences on routes onto Incapacity Benefit

Whilst flows onto Incapacity Benefit have subsided in recent years, these have been offset by the decrease in off flows from Incapacity Benefit. Management data from the Department for Work and Pensions (DWP) for 2001/02 illustrate that over 50 per cent seem to flow onto Incapacity Benefit from being out of work immediately before their claim (see also DWP, 2006). The research aims to consider factors such as people's medical conditions, experience of paid work, and the support or lack of support from family, friends, employers, health care and treatment services.

The following section examines evidence within existing literature and is presented around a series of key issues pertinent to understanding claimants' experiences of moving onto Incapacity Benefit: the role of health, and the role of key actors including employers, medical professionals, family and friends and Jobcentre Plus staff.

### 2.3.1 Health

Hedges and Sykes (2001) suggest that people who move onto Incapacity Benefit are not a homogenous group and that their characteristics, circumstances, perceptions of, and strategies for, dealing with their ill-health vary widely, which has implications for a return to wellness and their future return to work. For example, people may have conditions which are:

- short-term or one-off occurrences from which they expect to recover;
- acute, requiring long-term treatment;
- fluctuating or degenerative, involving intermittent periods of ill-health over long periods of time;
- complex, perhaps with multiple or secondary conditions.

A key issue for those at risk of being, or who have been, signed sick concerns being able to access appropriate and timely health treatment. Where such treatment is not forthcoming then this may have implications for people either returning to employment or seeking employment. Similarly, Stanley (2005: 38) argues that rehabilitation services for people who become disabled are currently *'highly fragmented, uncoordinated and poorly resourced and that the health service has neglected employment in relation to healthcare'*.

### 2.3.2 Employers

People who are affected by poor health, injury or disability are at risk of losing their jobs rather than being retained in employment (TUC, 2002). In a study of responses to the DDA, Roberts *et al.* (2004: 2) found for example, that 47 per cent of employers reported that they would find it *'difficult to retain an employee who became disabled'*. Research suggests that employers who encourage rehabilitation (for example, by having designated reintegration services or offering additional paid

leave) are more likely to be successful at reintegrating employees back to work after a long-term absence due to sickness (TUC, 2002).

Nice and Thornton's (2004) report into the management of long-term sickness suggests that there is a range of responses to sickness absence. For example, some employers took disciplinary action in cases where perceived 'non-genuine' days off were taken by staff, and this was also found to be the case where short-term absences were repeated. On the whole, however, the authors report that employers are generally sympathetic toward long-term absences, although there was evidence of some scepticism toward those conditions attributed as stress-related. However, some managers reported that they were more 'sensitive' to the needs of employees who were absent due to stress or depression (2004: 13). Across the participating organisations, widespread concern was reported with regard to retaining staff in order to '*keep specialist skills, maximise investment in training, avoid costs of recruiting and training new staff*' (2004: vii) and to project the message that employees are valued. Trying to engender a 'caring' ethos was a particular concern amongst human resources staff in organisations that had previously been intolerant of long-term absences. The involvement of in-house occupational health personnel was seen as beneficial to this end and some organisations contracted counselling services or bought in specialist services (such as physiotherapy, chiropractors or MRI scans) on an individual basis. Managers seemed to appreciate the existence of, and advice from, dedicated human resources or occupational health staff that may have implications for those workplaces without them.<sup>7</sup> However, research into job retention and rehabilitation suggests that occupational health services attached to employers might, from the employees perspective, be viewed ambiguously: providing help and support but as ultimately 'on the side' of the employer.

It was reported that organisations had procedures that would allow for retirement on health grounds which came into effect after many months in serious cases or where efforts to get the individual back into work had failed. Redeployment was presented as an option, but recognised as being 'unworkable' where it involved moving from manual labour to desk-based jobs. People with cardiovascular conditions, it was suggested, would be steered toward medical retirement or state benefits in such circumstances (Nice and Thornton 2004: 14).

As stated, health condition and the role of an employer will influence whether someone is more or less likely to go onto Incapacity Benefit. The Omnibus Survey (2003) highlighted that 19 per cent of people who had been off work sick for a week or more said that they felt their job was at risk. However, as noted in Chapter 1, those who come from the category 'work' constitute roughly half of the on flow to

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<sup>7</sup> The authors note that due to sampling issues their sample was overly reliant on large organisations (2004: 11). In terms of drawing implications for the present research, it should be noted then that Nice and Thornton's (2004) findings may be more applicable to those employers with access to occupational health/human resources.

Incapacity Benefit. People also flow on from other states of economic activity (for example, Jobseeker's Allowance (JSA)) and from economic inactivity (for example, early retirement, full-time education, or being a full-time carer (with or without having been in receipt of benefit)).

### 2.3.3 GPs and other medical professionals

In a study exploring how GPs worked with patients on sick leave, Mowlam and Lewis (2005: 3) whilst identifying a range of strategies for addressing patients' motivations to work, found four main factors which, to varying degrees with different GPs, constrained the involvement of GPs in 'return to work issues' (2005: 2). These included the importance of maintaining the doctor-patient relationship (and its stress on trust and an underlying assumption that the GP will act in the patient's best interest); the difficulty in providing continuity of care and gaining an in-depth knowledge of a particular patient; shortage of time in consultations and a limited experience of occupational health (which raised difficulties for them in giving advice about the interaction between a specific condition and the work a patient did and brought up concerns about possible litigation).

The widespread view amongst GPs was that *'patients' motivations for seeking sickness certificates were almost always genuine'*, however, some patients were considered to fall into, what GPs termed as, 'the sick role' (Mowlam and Lewis, 2005: 14-15). This referred to a set of responses to ill-health where patients *'do not see themselves as responsible for their own condition; see their illness as exempting them from their usual everyday functioning; do not necessarily see illness as an undesirable state; and do not feel a strong obligation or motivation to recover'* (2005: 15). Thus, the longer the patient was absent from work, the harder it was considered for them to move back into work.

Erens and Ghate (1993) found that only a quarter of people claiming **long-term** Sickness Benefit reported discussing returning to work with their GPs. However, GPs participating in the Mowlam and Lewis (2005) study acknowledged that lengthy absences from work due to illness can have negative psychosocial effects. A recurring view amongst GP respondents was that the activity of working and the financial independence it brings contributed to increasing patients' self-esteem and self-respect, social inclusion and their sense of being valued. Conversely, sickness absence was widely thought to pose a risk to people's mental health, explained, in part, by the lack of routine and social interaction resulting from being off work (2005: 12).

### 2.3.4 Household members and friends

There is little evidence to suggest how other household members affect the way that Incapacity Benefit claimants view their conditions and/or their feelings about work, although only eight per cent of respondents involved in Woodward *et al.*'s NDDP eligible population study specifically stated that their families did not want them to work (2003: 32). Data indicate that ill-health factors, combined with caring



responsibilities (for partners or relatives), can form barriers to the labour market (Alcock *et al.*, 2003).

In relation to the potential role of friends or peer group, Hedges and Sykes (2001), present data to suggest that friends can play an important role in terms of maintaining social inclusion and proximity to the labour market. For example, respondents gave examples of how friends had encouraged them to get out of the house and engage in social activities, such as hobbies and socialising. Some respondents also noted the role that friends can play in helping them find work, either by offering a few hours work in their own businesses, or by alerting them to vacancies in their workplace and making recommendations to potential employers.

### 2.3.5 Jobcentre Plus staff

Few respondents involved in Hedges and Sykes' study and the Incapacity Benefit Reform pilots mentioned contact with Jobcentre Plus staff and where they do, the information lacks depth. Some respondents reported having been encouraged by staff to see their GPs and 'claim sick' (Hedges and Sykes, 2001: 42). Respondents who did mention staff indicated varying degrees of empathy, helpfulness and advice.

## 2.4 Labour market detachment

Alcock *et al.*'s (2003) work on how men become detached from the labour market highlights that the process was often gradual and complex, and involved issues concerning the labour market, health and family. One of the most striking findings of their analysis was the complexity of any individual's circumstances and few of the detached men could attribute their situation to a single cause: rather, it was an interaction of family situation, health, labour market conditions and welfare benefit arrangements (2003: 186).

They further highlight that the initial trigger that leads to labour market exit can actually be different from the circumstance which prevents labour market re-entry. As Yeandle (2003: 186) notes, '*the destandardisation of retirement, of family structures and of working life as a whole presents a complexity of social risks*' and needs. Whilst Alcock *et al.*'s (2003) research is specific to male labour force detachment and Incapacity Benefit receipt, Fothergill and Smith (2005: 15) intimate that some of the above factors may be relevant as women increasingly share the same labour market (and structurally speaking, it may be added, the same health service) as men.<sup>8</sup> Increasingly then, men and women (especially younger cohorts) are

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<sup>8</sup> But, as a starting point, see Beatty and Fothergill (2003) in relation to 'the seaside economy' which does include women. One main justification to date for not including women in (not only) in-depth work is that the detachment of males from the labour market stands in stark contrast to the attachment of women over the past 20 or so years (see Alcock *et al.*, 2003).

in competition for the new generation of jobs in call centres, retailing, public services and the service sector more generally. Men and women compete for jobs and it is those with health problems who lose out.

## 2.5 Influences on routes off Incapacity Benefit

As previously noted, 43 per cent of claimants move off Incapacity Benefit within six months of their claim (Zerdevas, 2004). Ashworth *et al.* (2003) report that 76 per cent of their NDDP respondents strongly agreed that having a job was important to them. They note that one month prior to registration on the NDDP, 88 per cent of registrants wanted to work, including five per cent who were working (2003: 40). The experiences of many participants in the Job Retention and Rehabilitation Pilot (JRRP) indicate that amongst those who are at the point of moving onto Incapacity Benefit, the commitment and expectation to return to work is particularly high.

Those who had experience of paid work – however distant that experience might be – appear to view it positively. According to Loumidis *et al.* (2001), claimants' reasons for wanting paid work include:

- financial;
- self-respect;
- to keep occupied;
- to be normal;
- to enjoy work;
- to improve health;
- to get off benefit.

Seventy-four per cent of respondents in the study indicated that finance was a motivator and some respondents in the Incapacity Benefit Reforms and JRRP panel interview reported financial concerns precipitated by a decline in income, some having to sell or consider selling their homes as a consequence. Additionally, 62 per cent of Loumidis *et al.*'s (2001) NDDP participants stated that keeping occupied was important. This is consistent with some participants involved in the JRRP and Incapacity Benefit ('Pathways to Work') pilots who noted the therapeutic benefits of work. It should be noted, however, that some claimants were not looking to re-enter the labour market. Early findings from the Incapacity Benefit Reforms Pilots indicated that these are people who were either close to retirement, reluctant to come off benefits to face paying debts, or felt that their health would always be an obstacle to employment (Corden, Nice and Sainsbury, 2005).

Alcock *et al.*'s (2003) analysis suggests that people may experience complex periods of (secure and insecure) paid work and benefit receipt. For example, they highlight people in their 50s whose past working environments had contributed to their (sometimes multiple) health conditions who were on incapacity benefits at the time

of their survey subsequently being in fixed term and agency work by the time of the second interview. For example, a builder who had back problems and had been on Incapacity Benefit for five years went to work via an employment agency delivering parcels because he knew that they were very unlikely to ask him to have a medical (and he was sure he would fail one). In sum, *'there are differences between places, and differences in individual biographies and work histories. These all contribute to an uneven, differentiated and complex labour market'* (2003: 247).

Loumidis *et al.* (2001: 87) identified a range of barriers to the labour market for most Incapacity Benefit claimants. They note that people often have considerable and permanent health conditions which could be exacerbated by the presence of a secondary condition. Moreover, health problems often combined with other factors such as low educational attainment, caring responsibilities, restricted access to transport, limited work experience and having a partner with ill-health. Few of Loumidis *et al.*'s respondents, thus, felt able to work.

## 2.6 Conclusion

This chapter has highlighted and discussed a range of factors which will be important to consider in understanding the differentiated and complex processes and routes by which people move onto, stay on and leave Incapacity Benefit. As seen, in tracing routes onto the benefit, the literature suggests that it is important to situate people in their social context in terms of their labour market opportunities, health conditions, and access to healthcare and wider social networks.

The following chapter presents the first of the three routes identified to Incapacity Benefit and considers those people who make the transition from work to Incapacity Benefit.

## 3 Moving from work to Incapacity Benefit

### 3.1 Introduction

Within the group of people in our sample whose route to Incapacity Benefit was preceded by a period in work we have identified two sub-groups: people who have had (a) a gradual or (b) a sudden change in their health status. These sub-groups emerged from analysis that showed differences between people who had some warning and/or knowledge of their (often deteriorating) health condition and those whose illness or condition was more sudden in nature and caused them to go off sick or leave work abruptly.

The chapter presents the detailed analysis of the two main sub-groups in the route from work to Incapacity Benefit, starting with those whose route to Incapacity Benefit is preceded by a gradual change in health status.

### 3.2 Gradual health change and the route to Incapacity Benefit

As outlined in Chapter 1, people often took a route towards Incapacity Benefit that could, in broad terms, be conceptualised as a 'gradual' departure from work. As used here, the definition of gradual encompasses the fact that these people had existing and, in some cases, deteriorating health conditions which they were in some way attempting to manage via a number of strategies.

Among the 60 people in this study, 31 fell into our categorisation of a gradual health change, 17 of whom were men and 14 women. There was a wide range of health conditions reported by people in this sub-group most of whom were able to give diagnoses or descriptions. Some people reported more than one condition. The main health conditions reported were:

- musculoskeletal conditions (including arthritis, back problems, spondylosis, shoulder and arm problems);
- mental health problems (including stress, anxiety and depression, dementia);
- cardiovascular conditions (including heart attacks, angina, anaemia, hypertension);
- respiratory illnesses (including asthma, pleurisy);
- other varied conditions (including Crohn's disease, diabetes, hernia, multiple sclerosis, MRSA, ulcers, sciatica).

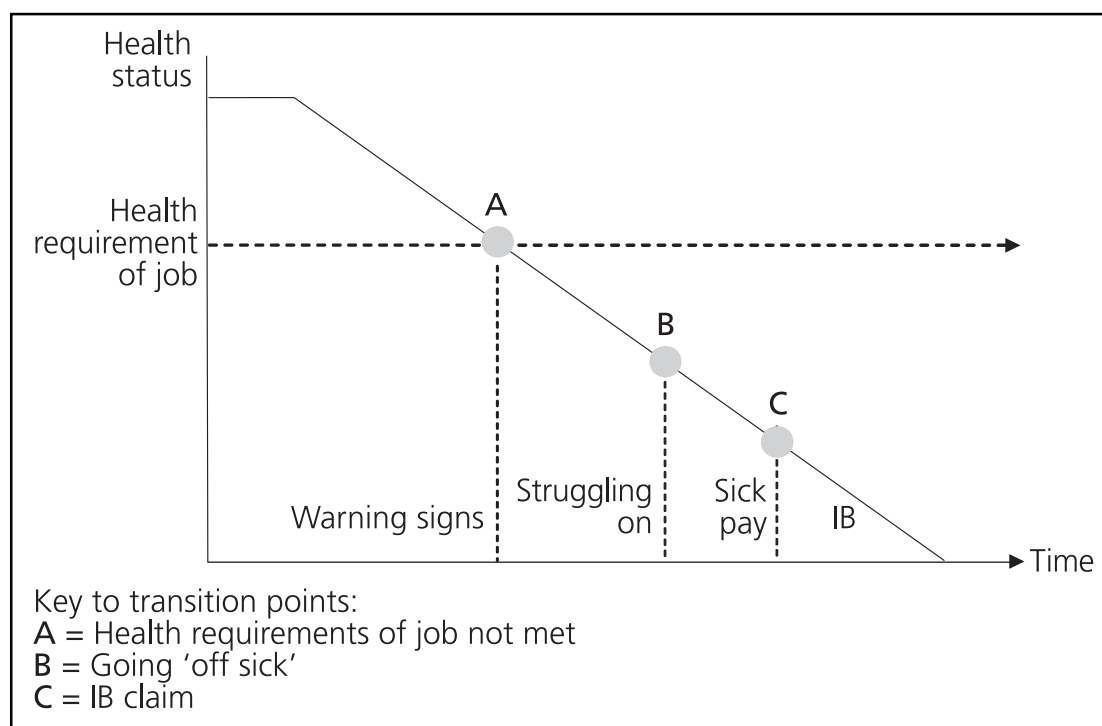
People were employees or self employed in a range of occupations including skilled and unskilled factory work, teaching, health care professions (including nursing, physiotherapy, podiatry), other service sector jobs (including postman, hairdressing, retail work, chef), and miscellaneous others (including farming).

### 3.3 The period prior to going off sick for people with gradual health changes

We are drawing here on data from the people in our sample whose route to Incapacity Benefit effectively began with a gradual change in health.

We can represent the route from working to claiming Incapacity Benefit diagrammatically in the following way by plotting health changes against a line representing the health status required to fulfil the functions of a job and identifying the transition points on the route.

**Figure 3.1 From work to Incapacity Benefit: gradual health change**



As mentioned in Chapter 1, the transition from a period when a person's health is declining but they are still able to fulfil the requirements of their job to a period of 'struggling on' when coping strategies are adopted, is not a clear cut one in practice. In this section, therefore, we present data from people's accounts covering both these periods up to the point they go off sick.

Even though people were in different stages of diagnosis and treatment (some of whom reported that they had been misdiagnosed or were still awaiting diagnoses), the period that we refer to as the 'struggling on' period was often characterised by their use of strategies to remain in work for as long as possible. Such strategies included hiding or dismissing symptoms; attempting to manage pain and exhaustion by, for example, asking GPs for strong pain killers; accepting colleagues' offers of help at work; and doing very little outside of work. Others approached, and sometimes pressed, employers for adjusted roles, and health services for diagnosis and treatment. What these findings illustrate are the lengths to which some people would go to retain employment. The following sections discuss the roles that key players take in the period up to going off sick.

### **3.3.1 Contact with GP and NHS services before going off sick**

People in this sub-sample had varying experiences of contact with GPs and other health services. Everyone in the sample had had some contact with their GP or other health professional, although contact could be very limited. For example, some people had an initial meeting with a GP at which they were given a sickness certificate but had no direct, face-to-face contact after that. This happened when people were referred to other health professionals for treatment or further diagnosis, or when the GP continued to issue certificates without seeing the patient. Some people did not expect to see their GP while they were attending a series of appointments at hospital or after they were placed on waiting lists. Occasionally there was no contact with GPs during the periods of 'warning signs' and 'struggling on'.

The ways in which people used their GP in this time period differed. In part this may have been contingent on the relationship already established between doctor and patient. For example, some people reported that they had had the same GP for a number of years, whilst others said that they hardly saw the same GP twice. While some people were reluctant to talk about their fears or symptoms to anyone (including their GP), others reported that their GP had been 'brilliant' in taking their fears and concerns seriously. In a few cases, people thought that they had been misdiagnosed by their GP. For example, a health care worker who also cared for one of her immediate family members was told that her physical symptoms were the result of stress, but occupational health services subsequently identified a viral infection which was causing lung and muscle disease. Similarly, GPs appeared not to pick up on relatively serious heart conditions in two men who were becoming increasingly ill. GPs were also reported to prescribe medications and to treat long-term conditions in this time period.

Some people also had contact with other health services prior to going off sick, including referrals to hospital consultants, treatments (for example, from physiotherapists or mental health therapists), and diagnostic tests. However, where people were referred onto hospital specialists by their GPs, waiting times for consultation, diagnosis and treatment could become a major problem. There were references to waiting lists for consultants of anything from six to 18 months. Some people also remembered being warned by medical professionals at this time to stop work or change their employment. Such advice could be stark and uncompromising. One person was told by a consultant that he would 'end up in a wheelchair' if he did not stop work completely. Another was advised by their GP not to drive long distance vehicles and an osteopath treating a chef with a musculoskeletal problem advised her to change professions.<sup>9</sup>

On the whole the periods of 'warning signs' and 'struggling on' seem characterised by GPs mainly being concerned with immediate treatment or making referrals for tests and investigations. There were few reports of work being discussed at all. Where it was discussed it appears that GPs advised people that continuing to work would be possibly detrimental, or dangerous, to their health. This advice was not always heeded immediately. For example, one person who was seeing her GP for stress-related symptoms due to workplace bullying was advised to stop working but decided to continue, but a month later went off sick.

### 3.3.2 Employment conditions and employer relations

Strategies employed by people to cope with the demands of their jobs seemed to vary according to the interaction of their condition with their day-to-day work environment. In some cases, manual workers coping with physical pain were assisted by colleagues sometimes with, and sometimes without, the support and facilitation of an employer. Some manual workers for example, feared losing their jobs if they disclosed their condition to management (a fear not completely unfounded as later sections of this chapter highlight) and in such instances it was not unusual for colleagues to informally agree on carrying out certain tasks in a participant's stead such as the lifting of heavy items. 'Not telling' was also in evidence in cases of mental ill-health where a build up of stress arising from outside or inside the workplace (or a combination of both) could lead to a sudden departure from the workplace. Some of those who did not inform their employers about their illness or ask for an alternative role at work were employed via agencies on short-term contracts.

In other instances, employers were made fully aware of their employee's (deteriorating) health condition and responses to requests for lighter or alternative roles varied from dismissal or redundancy to making efforts to accommodate the employee. For

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<sup>9</sup> Both of these people did not take this advice or were in the process of making a career transition when they reached a point at which they could not continue and were signed sick from work.

example, whilst not dismissing an employee on health grounds, employers were reported to refuse requests for altered working conditions outright, which made it impossible for some people to carry on in their work environment with their condition. One person explained that she had, upon taking up her position of employment, been assured by the employer that the work was not heavy and that she would, thus, be able to manage her condition of arthritis. However, the work turned out to be very heavy for her and the manager concerned was unsympathetic to her request for lighter duties. Further examples include a chef being refused time off to prevent exacerbating a musculoskeletal problem because it was a busy period for the employer, and of a civil servant's request to accommodate his condition by working from home refused because, as he explained, he was not of a high enough grade.

There were instances where people felt that their employers did try to accommodate their condition. However, the nature and/or severity of conditions at the time meant that some people could still not cope with their condition with a lightened work role. For example, a skilled manual worker with a heart condition was told by his employer that he need not rush when he had chest pains and that regardless of the fact that it would take him longer, he should use a crane to lift heavy engine parts, but he was still unable to cope. This example perhaps highlights the importance of being able to take on an alternative, rather than a lightened, role in this time period. One instance of this was a factory worker who was given an assistant so that he did not have to lift things and was told by his employer that he should only do computer-based work whilst he was in pain.

Three people in this sample were self-employed but their experiences of ill-health up to the point they stopped working was similar to paid employees. They struggled on, making some adjustments where they could, but then ultimately reached a point at which they could not cope with work any longer.

For some people (working for larger employers like the National Health Service) occupational health services were available and used in the 'struggling on' period. For example, in one case occupational health diagnosed a health condition which had been missed by the employee's GP. There were also examples where occupational health, often in consultation with the employee, had informed line managers of alternative roles that might be performed.

### **3.3.3 Role of family and friends**

On the whole it seems that friends and immediate family (for those who had them) tended to encourage people to look after themselves and to put their health before their work. This was especially so in cases where they had been told by medical professionals that they were damaging their health by continuing to work.



### 3.4 Experiences of employees while off sick prior to claiming Incapacity Benefit

The period of being off sick is important because it presents opportunities to avoid the need for someone eventually to make an Incapacity Benefit claim.

People had very varied experiences of the period of being off sick from work and in receipt of Occupational Sick Pay or Statutory Sick Pay (SSP) up to the point of making a claim for Incapacity Benefit. For some, the period was relatively lengthy during which time they had contact with health services, employers and possibly others, such as Jobcentre Plus staff. However, it is also important to recognise that for some people this period was very short, and in a few cases, there was effectively no period of 'being off sick' because their paid employment ended at the point of first going off sick. In effect, at this stage, a number of people in the sample were sacked, made redundant or left work voluntarily.<sup>10</sup>

#### 3.4.1 Contact with GP and NHS services while off sick

At the point of going off sick, or very soon afterwards, most of the people in this sub-group were issued with a sickness certificate by their GP. This was either requested by them or offered by the GP. Often, people spoke about going to see their GP when they had reached some kind of breaking point – for example, a participant with a musculoskeletal condition went to see her GP 'in tears' when she was experiencing migraines and exhaustion resulting from not sleeping. She had got to the stage where she could not grip everyday items such as an umbrella, let alone medical instruments at her place of work, and had started to spill pans of hot water at home. Her GP then signed her off sick.

For some people it was hard to distinguish the period before and after making a claim for Incapacity Benefit. For them it was more salient to talk about a single period of being away from work while sick. The point at which they claimed Incapacity Benefit had no bearing on the trajectory of their health condition. Hence, people talked about using a wide range of health services, including referrals to hospital consultants, treatments and diagnostic tests. Being on waiting lists was a common experience and there were examples of GPs lobbying hospital consultants on behalf of patients when they had been informed they would be waiting a considerable time either for an appointment with a consultant or for treatment.

Having entered a period off sick, the subject of returning to work was not, according to the research participants, raised by their GPs. Some people, however, said they had raised it themselves, asking advice on when a return to work might be possible, or what duties they might be capable of while they were either stable or recovering from a health condition. In such cases, people reported that their GPs were

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<sup>10</sup> The Omnibus Survey 2003 suggests that 19 per cent of those on sick leave felt that they felt their job was at risk whilst on sick leave for more than a week.

responsive and either encouraged or supported the desire to start some form of working again, or advised that work was not yet appropriate. A few people had similar experiences when they raised the subject with work or with other health professionals such as physiotherapists or community psychiatric nurses (CPNs). In contrast no-one reported that they discussed work with hospital consultants (although one person said he planned to ask his specialist what he might be capable of when he had his first appointment with him).

### **3.4.2 Employment conditions and employer relations**

How people were treated by their employers while off sick varied. Where employers kept in contact with employees to find out how they were, employees often took this as a sign that they were valued in their job. Similarly, where no contact was forthcoming from the employer, people could feel that they had been 'forgotten about' and feel devalued. Exceptions to this were found in cases of conflict in the workplace (for example, a participant who perceived that they had been bullied wanted no contact from anyone at work and felt 'hounded' by phone calls from their employer). At this stage, some employees requested an alternative role to suit their reduced capabilities. However, there were very few successful examples of this actually happening. People in the sample reported that their employers cited, for example, the cost of replacing them or the limited scope for other roles as reasons for inaction.

People had different experiences of occupational health departments. For some, occupational health staff effectively performed the role of informing the participant that they were not fit enough to do their job and referred them to their GP for a sickness certificate. In contrast, some employees signed off by their GP subsequently went to their occupational health department or were called in to see them. In such cases, people valued the confirmation that they were indeed unfit to do their job and in certain instances actively consulted with occupational health staff in order to approach the appropriate people within the organisation with a view to getting an alternative role.

Views regarding occupational health were contextual and sometimes depended on people's relations with their employer. While generally speaking, services and benefits were viewed in a positive light by the people in the study, there was also a (sometimes strong) perception that occupational health staff were ultimately on the 'side' of the employer. In some cases they had recommended early retirement on health grounds.

In contrast, the small number of people who had accessed occupational health services through their GP surgery rather than through their employer did not report such perceptions and were positive about the benefits gained. In such instances for example, occupational health services had helped with support, information on entitlements to benefits and advice on employment legislation. In one case they had contacted a small employer to inform them of their contractual obligation to pay their employee sick pay for longer than the period actually offered.

### **3.4.3 Role of family and friends**

In this time period it was mostly the case that people reported receiving emotional and (depending on circumstances) financial support from family and friends. However, there were also some tensions for some people including spouses and partners having to 'bear the brunt' of a participant's frustrations concerning their ill-health. Some people also reported being worried about their family's financial situation and a sense of anxiety about what would happen if they were unable to return to work soon.

## **3.5 The transition to Incapacity Benefit**

If we conceptualise the transition to Incapacity Benefit as a step in the process of labour market detachment, it becomes important to understand the major factors involved for people in making this transition. The sections below highlight that the transition from being off sick to going onto Incapacity Benefit was made by people in a number of ways and outlines a number of key (and in practice interrelated) factors.

It is important here to reiterate the different time periods in question. As we have discussed, some people reach the point of claim for Incapacity Benefit immediately on going sick from work, whilst others have had between three to 12 months of Occupational Sick Pay and/or SSP. Some people with a continuing contract of employment still considered themselves 'off sick' whilst in receipt of Incapacity Benefit. This suggests that some employees are at much greater risk of labour market detachment than others when they become ill.

The point of transition to Incapacity Benefit was, therefore, mainly tied to an employer's arrangements for paying sick employees. Within this sub-group of our sample we did not find evidence of GPs or health workers having a role in the transition.

### **3.5.1 Role of employers in the transition to Incapacity Benefit**

Where people were employed and had received Occupational Sick Pay and/or SSP for a period of time, employers often included information on Incapacity Benefit in with their last (sick) pay advice. Whilst a number of people still retained a contract of employment at the time of their Incapacity Benefit claim, it is at this transition point that some employers started procedures to terminate employment on health grounds and a minority of employees gave notice to leave on health grounds.

Of the 36 people in total coming to Incapacity Benefit from work by the time of their Incapacity Benefit claim (or just after in some cases), seven people had been or were in the process of being dismissed, made redundant, were on a temporary contract that was coming to an end or were working with agencies and effectively had no contract of employment. One participant had already given in her notice to quit her job on health grounds and a further three people gave their notice when they found out the severity of their illness. One participant felt 'obliged' to give in her notice

after receiving SSP for six months. Two people had been employed and went straight back onto Incapacity Benefit under the Incapacity Benefit linking rules when their health deteriorated in work. One participant was sent for three medicals by his employer and when he could not provide them with a firm return to work date within a given time period, proceedings to sack him on health grounds were instigated. In a further two cases it was not entirely clear as to whether employer or employee had instigated the termination of employment at the Incapacity Benefit claim point. In total, therefore, half of the research participants coming from employment at the time of their Incapacity Benefit claim effectively had no job to go back to.

### **3.5.2 Role of Jobcentre Plus staff**

At this time point, most people who come from work will have made some kind of contact with the Department for Work and Pensions (DWP) call centres or Jobcentre Plus offices (and one participant mentioned that she had called the Disability Information and Advice Line and had got help to fill in the personal capability assessment form). The range of contact experienced by people varied from one telephone call to a series of face-to-face meetings. Those who had had very limited contact had mostly made their claim by post (having either received the forms from their employer or having phoned up and had the forms sent through the post). Other people had made a number of enquiries about Incapacity Benefit prior to claiming and yet others had been called for a Work Focused Interview.

It was common to find that those whose application had in some way been problematic had to make repeated phone calls and/or visits to offices. People got confused by the number of different places associated with the administration of benefits and sometimes had been unsure about where they should hand in a claim form or sickness certificate, resulting in a delay in payment. In yet other instances, people recounted being misinformed about how and where to claim Incapacity Benefit, and about delays in payment of benefit. Some felt strongly that Incapacity Benefit claim procedures were degrading and others perceived staff as intrusive and as acting as though under strict instructions not to tell potential claimants about benefits that they might be entitled to and instead try to get people into any kind of job that would reduce the claimant numbers.

### **3.5.3 Family and friends**

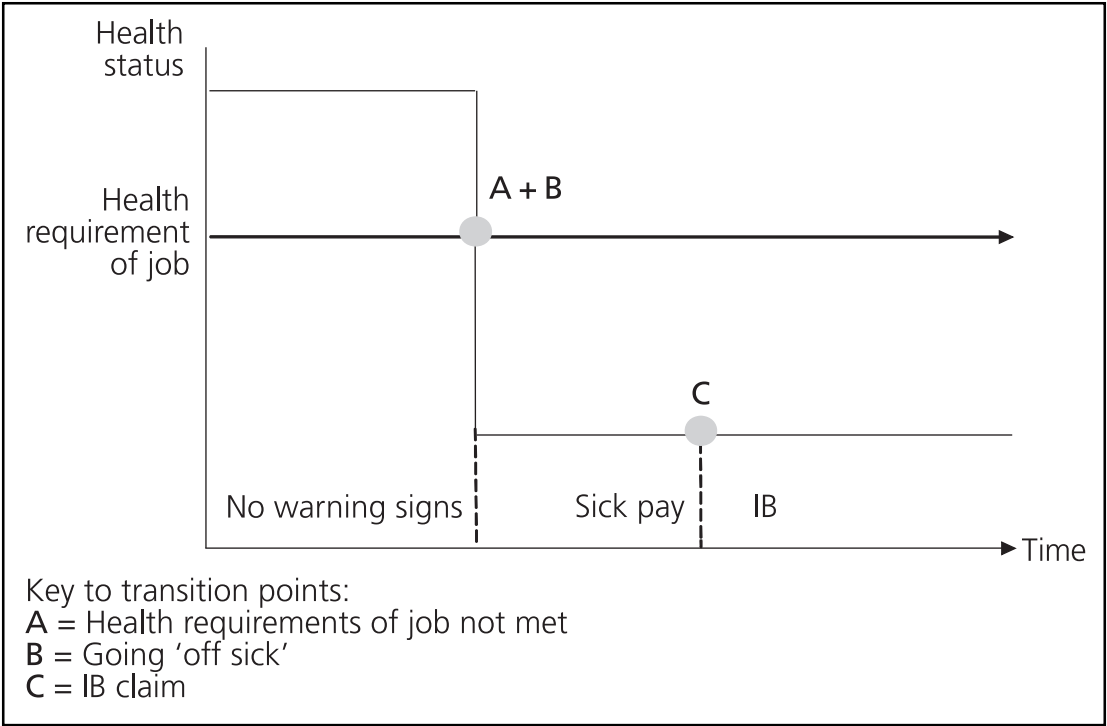
Families' major role seemed to be to provide care and support (material and emotional) which sometimes included a long-term altering or adjusting of home life. For example, one person's daughters and husband made sure to arrange their mornings so that someone was there to assist her in dressing. Depending on the length of time on Incapacity Benefit, some people felt pressured to contribute to the family finances.

### 3.6 Sudden health change and the route to Incapacity Benefit

In this section we are drawing on data from five people in our sample of 60 whose route to Incapacity Benefit was precipitated by a sudden change in their health status.

Included here are people who went sick from work because of an accident (whether at or away from the workplace) or the unexpected onset of a health condition. One of the main points to make here is that the opportunities to retain employment may sometimes be harder with the onset of a sudden – and in a lot of cases here – quite severe condition, thus leaving fewer options in terms of policy interventions (except where accidents at work are concerned, which may have implications for health and safety legislation). Effectively, for this sub-group the transition periods ‘struggling on’ and ‘going off sick’ merge.

**Figure 3.2 From work to Incapacity Benefit: sudden health change**



Four of the people who experienced a sudden health change were male and one was female. Two of the men had had accidents. One had sustained injuries in a work-related accident whilst the other had been involved in a road traffic accident outside work. Two had previously undiagnosed conditions, the symptoms of which (for example, a heart attack) necessitated an immediate departure from work. Some people had not had diagnoses of their health condition at the time of their initial research interview.

The range of occupations in this category included skilled and unskilled: a factory worker, a health care assistant, a driver, a manager and a domestic appliance engineer.

### **3.6.1 The period prior to going off sick**

Given the sudden nature of the illnesses and accidents for people in this sub-group there was no period in which they were aware of the 'warning signs' of a deteriorating condition, nor a period of 'struggling on' during which they tried to cope with the effects of their condition. The transition from working to a period of sickness leave was very rapid if not immediate. There were effectively no opportunities for discussion about whether they should take sick leave with employers, medical professionals or friends and family.

### **3.6.2 Being off sick prior to claiming Incapacity Benefit**

In some ways, the experiences of people in this sub-group after going off sick were similar to the experiences of those who had more gradual changes in health. One qualitative difference, however, is that for most of the people who left work because of a sudden change in health condition, the change also tended to be serious in the sense that their prognosis was uncertain and the prospects of a speedy recovery very unlikely (for example, heart attacks, strokes, serious accidents). The exception here was the person who suffered a broken limb, whose condition was clear and his prognosis was relatively easy to foresee.

All of the people in this sub-group had been on some combination of Occupational Sick Pay and/or SSP for varying lengths of time before their Incapacity Benefit claim. The point at which they claimed Incapacity Benefit was, therefore, not linked to their health trajectories but to their sick pay arrangements.

### **3.6.3 Contact with GP and NHS services while off sick**

GPs and NHS services were of obvious and major importance for all the research participants. However, for those without access to occupational health services, it might be argued that they gain in importance in terms of providing information and advice about specific health conditions and capabilities (abstaining from or returning to work, recommending alternative work roles) and benefits. Evidence from this study suggests, however, that people did not, on the whole, consider it the role of the GP to initiate in-depth conversation concerning their capabilities for work.

On the whole, this sub-group had found their GP supportive in relation to issuing sickness certificates, providing health care and in referring them on to hospital specialists for diagnosis or treatment. Major difficulties, however, were experienced in regards to hospital treatment. People reported having to wait for several months for consecutive appointments with NHS consultants, hospital investigative scans and follow-up appointments and treatment.

### **3.6.4 Employment conditions and employer relations**

Those coming from work who had been receiving Occupational Sick Pay or SSP for any given period of time often reported that their employer had included information on (how to claim) Incapacity Benefit in their last pay advice from work. Most people, thus, talked about their claim as being the next step in terms of maintaining an income out of work whilst they were unable to return to their job. The majority of those in this sub-group reported that their employers had, on the whole, been supportive (with the exception of the person who had sustained the accident at work) and no one reported having their employment terminated outright because of their ill-health.

Employers maintaining contact with employees and enquiring about their welfare was, when perceived as initiated out of concern and appreciation for the participant, much valued. This was especially so in the case of small businesses in which employees felt that their employers were also their friends. Further, many of this sub-group seemed to have felt reassured by their employer's offer to graduate the return to work, by, for example, arranging for them to do fewer hours per day, fewer days per week or less manual work.

On the other hand, a minority of the research participants perceived their employers as being 'awkward' at this stage and reported incidents where wages owed had not been paid on time; failing to inform DWP about the end of SSP and denying that they had received a sickness certificate. In some such instances, employees involved a union to try and get the employer to send appropriate documentation to DWP.

Where people had access to them, occupational health services seemed to play an ambiguous role and were often perceived by them as something of a double edged sword. On the one hand the medical services such as diagnosis in regard to employment capabilities, information and advice (concerning, for example, benefits) were often much valued by people. However, this was often accompanied by defensive feelings that occupational health staff could not be entirely objective about a participant's health because, by definition, they were ultimately on the 'side' of the employer.

### **3.6.5 Role of family and friends**

All of the people in this sub-group had partners who they said provided a great deal of support (both emotional and practical) and informal care. Sometimes, the suddenness or severity of an illness or accident necessitated a participant's partner stopping work or changing to part-time hours in order to provide care. In other cases, partners offered to work extra hours in order to make up for the shortfall in the household finances resulting from the participant's absence from paid work.

### **3.6.6 Role of Jobcentre Plus staff**

There were quite varied experiences of contact with Jobcentre Plus offices. Some people spoke positively about finding a member of staff that 'knew what they were

doing' and who they felt had excellent customer service skills. Those who still had a contract of employment, including a small number who had been called in for a Work Focused Interview after submitting an Incapacity Benefit claim, mostly reported that Personal Advisors provided information about tax credits and benefits that they might be able to apply for and then waived them from returning for any other meetings. In contrast others felt that they had been repeatedly 'messed about' by staff in that they had been given insufficient or misleading information.

### 3.7 Attachment to the labour market for those experiencing sudden and gradual changes to health

For some people, the transition to Incapacity Benefit coincided with them having to try and come to terms with very serious and terminal illness and its implications on all areas of their lives. As mentioned earlier, many of the people in this sub-group had been on some combination of Occupational Sick Pay or SSP for varying lengths of time before their Incapacity Benefit claim.

Whilst all were in different financial circumstances, it was clear that for most people (relative) financial need was a major reason for claiming Incapacity Benefit. People who were owner-occupiers sometimes had mortgage insurance packages covering them for redundancy and/or sickness absence, but others had neither. People were worried about how they would meet immediate outgoings such as mortgages, loan payments and day-to-day living expenses. Moreover, there were worries about the longer-term impact on their standard of living should they have to give up work completely on health grounds.

Work was a major part of people's identity and all of those in this group wanted to go back to work for a variety of different reasons: financial security, personal satisfaction, social contact and to provide a sense of structure to their day. Such feelings made it all the more difficult for those with chronic conditions who had been told that they should never undertake paid work again and for those whose long-term prognosis remained unclear.

Many research participants reported an effect on their mental health from being off work sick, citing reasons that mirror those given in relation to what people got out of work: the loss of structure to their day, the loss of personal contacts and the financial implications of moving to Incapacity Benefit. Conditions and symptoms ranged in severity (from 'feeling down' to having nightmares, flashbacks and panic attacks). Sometimes, the effects on mental health were a result of coming to terms with a traumatic illness or accident. People who still had contracts of employment but who were unfit to do their own job faced frustration with their lack of treatment or their lack of progress. It should also be noted that once on Incapacity Benefit, people's health could deteriorate as well as improve and some went on to be treated for other conditions. A minority who had reported experience of bad workplace relations (for example conflict with colleagues or perceived bullying) said that it was their job that was making them ill. Whilst they felt better away from the workplace they did not, at the time of the initial research interview, feel ready or able to return.



### 3.8 Discussion and conclusion

This chapter has presented findings from the sub-group of people in the study sample whose route to Incapacity Benefit was precipitated by either a gradual or a sudden change in health condition while in paid employment. The two groups experienced different trajectories up to the point of going off sick from work that have different policy implications, which we return to in the final chapter. Where people experienced changes in their health in a gradual way, we can identify stages in their trajectories that we have called the 'warning signs' phase and the 'struggling on' phase, both of which provide opportunities for preventive action that might avoid the need for a claim to Incapacity Benefit later. In contrast, both groups were likely to share similar experiences of being 'off sick'; another period that affords opportunities of job retention and rehabilitation.

Not surprisingly, people had sometimes extensive contacts with health professionals during the period up to and beyond the point of claiming Incapacity Benefit. This period was characterised for most people by a significant deterioration in their health to the extent that their functioning at home and at work reaches a critical (or 'transition') point at which they go off sick from work. For some in our sample this health change was sudden and unexpected, but for most it was gradual. People's accounts of dealings with GPs, hospitals and other health workers were, again unsurprisingly, dominated by the responses to their health conditions. Where there were discussions about work during the 'warning sign', and 'struggling on' phases, these tended to be about whether and when a person should stop working.

When people were actually away from work on sickness absence talking about when a return to work might be possible seemed only to take place when they raised it themselves. GPs and other health professionals did not raise the subject initially. A picture, therefore, emerges of them acting in a largely responsive manner, being led by patients' own aspirations and assessments of their own capabilities. There were no examples within this sub-group of the sample of GPs and others proactively promoting work as either a means of coping with ill-health (during the period prior to going off sick) or as part of the process of recovery once they were off work.

People's likelihood of experiencing a period off sick was linked to their labour market position. In the literature review in Chapter 2 we discussed the impact of structural forces on the numbers of people claiming and receiving Incapacity Benefit. The evidence from this study supports this analysis. People in low paid, low status insecure employment with little or no occupational benefits contrasted with those with more stable employment enjoying (differing degrees of) employment rights and benefits. This resulted in very different experiences of sickness absence. For example, the transition to Incapacity Benefit for those with rights to Occupational Sick Pay or SSP was made after having received (combinations of) full and half pay for several months and for some, up to a year. In contrast, for those without such rights the transition to Incapacity Benefit was made, in some cases, from the day they went off sick. Such differences have implications for the numbers of people flowing onto

Incapacity Benefit. If those in employment have no access to occupational sickness arrangements then one of their main options is to claim Incapacity Benefit.

For some people in the sample, the health condition that they experienced was linked to their employment. For example, manual workers tended to be among those who first claim Incapacity Benefit because of a physical injury or condition, whilst non-manual workers were more likely to be signed off with mental health conditions. What is clear from this research, however, is that as time progresses after the start of sickness absence many people can expect some kind of effect on their mental health, related to a range of factors including concerns about their health condition, financial worries, boredom, and the loss of routine and social contact that work gave them.

Among our sample there was some evidence of activity that could be described as job retention activity, but by definition none of this had prevented claims for Incapacity Benefit (as the sample comprised new claimants of Incapacity Benefit). In some instances an Incapacity Benefit claim was made soon after going off sick so there was effectively little opportunity for successful job retention activity. However, in other cases the actions of employers and occupational health departments, for example, in changing duties, were not sufficient to enable the employee to continue working.

As explained in Chapter 1, not everyone claiming Incapacity Benefit comes from employment. The next chapter begins to explore the routes onto Incapacity Benefit of people in our sample who were not in work immediately prior to their claim.



## 4 Moving from non-work to Incapacity Benefit

### 4.1 Introduction

This is the first of two chapters dealing with people who flow onto Incapacity Benefit from a 'non-work' status. This is an important group of people. As mentioned in Chapter 1 they constitute around half of new Incapacity Benefit claimants and the policy implications of their route to Incapacity Benefit might be different in comparison with people whose route is directly from employment (covered in Chapter 3).

In this and the next chapter we have distinguished between people whose 'non-work' status was relatively long and those who had been in work relatively recently, even though their status immediately prior to their claim was 'non-work'. Effectively, what we see are two ends of a 'non-work to Incapacity Benefit' continuum; respectively, those who have been out of the labour market for relatively longer periods of time at one end and those at the other end who have moved more quickly and more often between insecure employment (for example, in lower service sector jobs), unemployment and sickness benefits.

### 4.2 The route to Incapacity Benefit

Of the 16 people in this group, nine were men and seven were women. As we would perhaps expect, given that people in this group had, on the whole, been outside of the labour market for a longer period of time than those in the previous chapter, none of them still had a contract of employment.

Although all of this group had a 'non-work' status prior to claiming Incapacity Benefit there was wide variation in their circumstances. Some had been in receipt of social security benefits, including Jobseeker's Allowance (JSA) and Income Support (IS) (of these one had been advised to come off Incapacity Benefit and claim JSA and then reclaim Incapacity Benefit once her personal circumstances had changed; one

was on JSA because he had been taken off Incapacity Benefit on medical grounds and had subsequently appealed; and others were on JSA, had become unwell and had, therefore, claimed Incapacity Benefit). Others were not in receipt of any benefits but were receiving an occupational pension or were living off a redundancy payment. Others were supported entirely by their partners or family. Some had been full-time students prior to their claim.

The main health conditions associated with their Incapacity Benefit claim were as follows:

- pregnancy;
- cardiovascular: high blood pressure, aneurism;
- musculoskeletal problems: back problems, spondylosis, bone ulcers, debilitating muscle spasms;
- mental health problems;
- visual impairment;
- other conditions such as a hernia, arthritis, concussion.

Some of this sub-sample had multiple health conditions and others had fluctuating conditions.

Of those coming from a non-work status, three reported that they were on Incapacity Benefit for a short period of time because they were ineligible for Maternity Allowance; one person said she was advised to sign off Incapacity Benefit, sign on to JSA and then reclaim Incapacity Benefit because of a (short) change in her circumstances; two people had previously been advised that they did not have enough National Insurance contributions to claim Incapacity Benefit at the time they left work and had subsequently reapplied; and two people were awarded Incapacity Benefit as the result of an appeal. Some were only on Incapacity Benefit for a few weeks and were already off by the time of the first research interview. Some of those with fluctuating conditions had claimed Incapacity Benefit previously.

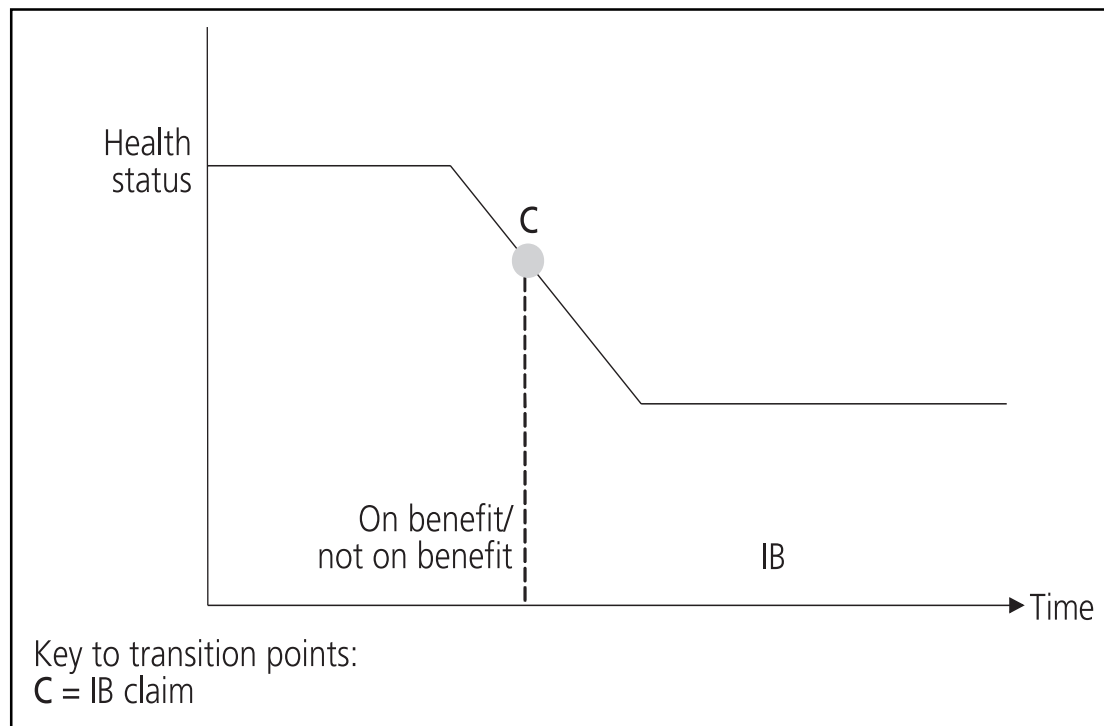
Some people were lone carers for their children, which in some instances, compounded their barriers to the labour market. Some people had recently experienced major crises in their life (which they were still coping with) and their health conditions were partly related to these experiences.

### 4.3 The transition to Incapacity Benefit

In Chapter 1 we introduced a framework for analysing routes onto Incapacity Benefit that included periods of 'warning signs' and 'struggling on' for people in work before going into a period of being 'off sick'. For people coming to Incapacity Benefit from 'non-work', however, these phases are largely inapplicable. For them, there are effectively only two periods that can be distinguished: a period prior to

being on Incapacity Benefit during which time they experience a change in their health status, and a subsequent period after successfully claiming. Figure 4.1 represents the route to Incapacity Benefit from 'non-work'.

**Figure 4.1 'Non-work' to Incapacity Benefit**



In the research interviews some people in this sub-group were able to recall their last period in employment. People remembered, with varying degrees of detail, periods of 'struggling on' and being 'off sick' and the roles of other key actors such as employers, and their access to occupational sick pay arrangements. However, the interviews focused on the most recent transition to Incapacity Benefit from their status of 'non-work' as being the most relevant for generating lessons for policy.

#### 4.3.1 Contact with GP and NHS Services

Within the group of people coming to Incapacity Benefit from a 'non-work' status, two types of proactive role for GPs were described. The more common role described was for a GP to, as several respondents put it, 'sign me off sick' when they went to their GP because they were unwell. There was not a great deal of recall here but a picture emerges that is familiar from other studies (for example, Mowlam and Lewis, 2005) of GPs asking patients of working age whether they required a sickness certificate. For some people it was at this time that they first appeared to learn of their potential eligibility for some form of sickness benefit, and it was only when they took their certificate to a Jobcentre Plus office that they were informed that they should claim Incapacity Benefit. The second type of proactive input from a GP (though only one person appeared to have this experience) went beyond the offer of a sickness certificate to positive encouragement to claim Incapacity Benefit. During

a consultation, her GP had suggested that she might want to think about applying for Incapacity Benefit after she had become extremely upset about her household financial situation and her worsening illness and the implications for her employment prospects. She had not claimed anything for over five months (during which time her partner had supported her) in the hope that she would soon be well and able to find a job. As mentioned, this was the only explicit example in the data of a GP encouraging an application for Incapacity Benefit. It was also the only example of a research participant describing a GP taking a more holistic view of the person's condition (i.e. linking it to wider household and financial circumstances).

People's recollections of contact with health services were otherwise mainly focused on how well (or not) they responded to their particular health needs. A range of research participants reported that their GPs were, in the main, 'supportive' and would sometimes lobby to get them access to treatment. Others stated that they rarely saw the same GP more than once. Long waiting times for hospital treatment and operations were also an issue for some people. There were some people whose conditions took a long time to diagnose and who had been passed from one specialist to another. One participant who perceived that his medical condition was a direct result of the manual work he had done, had undergone a second operation for it because the first one had not been successful. As in Chapter 3, there were also examples of people who, having initially been signed off with physical conditions (e.g. after being involved in a road traffic accident or having taken early retirement on health grounds), subsequently became depressed. Other people also developed secondary conditions (for example, MRSA and bed sores after having initially been signed off sick with an aneurism). Although not directly relevant to people's routes onto Incapacity Benefit we can see here again how lack of appropriate health care or having to wait for services can militate against people moving off Incapacity Benefit quickly.

It is clear that some people first learned about Incapacity Benefit from contact with their GP. There was also one example of a person gaining initial knowledge from a leaflet picked up in a hospital waiting room.

### **4.3.2 Role of Jobcentre Plus staff**

In many cases the initial contact with Jobcentre Plus was similar to those in Chapter 3 who came from work. It was not uncommon for people to phone up or call in person into the office to enquire about Incapacity Benefit or sickness benefits after receiving a sickness certificate from a GP and then be given the appropriate forms to complete. This sequence of events is in a sense unremarkable and can be considered as an example of the health and benefits systems working as they should.

For some other people in the study the first step towards Incapacity Benefit was contact with staff from Jobcentre Plus. There were a number of different examples here. The more common example was when a JSA recipient reported to an adviser that they were unwell (to the extent that their job seeking was affected). People reported being advised that they should, therefore, be claiming Incapacity Benefit

and that a sickness certificate was required for this. Again, we can identify an unremarkable sequence of events where people seemingly receive appropriate information and advice to match their circumstances to the requirements of the benefit system.

There were also examples of other types of advice being given to potential claimants. One woman's route to Incapacity Benefit started when she visited a Jobcentre Plus office to ask what she could claim whilst pregnant and unable to work. Another claimant wanted information and advice about benefits in general and about National Insurance contributions in particular after having left work through redundancy. Because of his age and his multiple health conditions he did not want to work prior to reaching retirement age. He was, therefore, advised that he would not be eligible for JSA but advised to claim Incapacity Benefit instead (which would also ensure the continuity of his National Insurance record). Two people in the sub-sample received a different sort of advice. In both cases they had tried to claim Incapacity Benefit at some point in the past but at the time were not eligible because they did not have sufficient National Insurance contributions in the relevant year. They both said that they received helpful advice from Jobcentre Plus staff about when next to make a claim so that they would satisfy the contribution conditions.

Otherwise recollections of contact with Jobcentre Plus for this group focused on what happened to them in the period between initiating a claim and receiving payment. People had a range of views regarding the way that they had been treated: some were positive but most were not. One person signed off with mental ill-health who had been called for a Work Focused Interview spoke of how the Personal Adviser had been 'lovely' and had left it up to her to come and enquire about opportunities to retrain whilst on Incapacity Benefit at her own pace. One other participant said that Jobcentre Plus staff had advised him to see someone from the local Citizens Advice Bureau and appeal against the decision to take him off Incapacity Benefit. One participant, again echoing comments from those in Chapter 3, felt fortuitous to have found a member of staff *'who seemed to know what they were talking about'*.

Others felt that benefits for sickness and disability were too compartmentalised and thought that, for example, staff who deal with Incapacity Benefit claims should give people all of the relevant information about what income can be claimed when people are unable to work because of illness. A participant who had spent six months in hospital spoke about how his wife had first contacted Jobcentre Plus to enquire about Incapacity Benefit once he had been in hospital for a month. She was told that he should claim once he came out of hospital and subsequently, this is what he did. Once he claimed he was told that he should actually have claimed when he was in the hospital. Another person with a visual impairment felt that his independence and privacy were demeaned by Jobcentre Plus not sending out correspondence or having job advertisements available in Braille for him to access. A few people mentioned that being called into the office for a Work Focused Interview was, given the nature of their condition, embarrassing for them and that they would have preferred to have been interviewed at home.



### 4.3.3 Family and friends

There was little evidence of family or friends being particularly influential in decisions to claim Incapacity Benefit. Rather, they were supportive in helping people respond to their health conditions. In a few cases, people had partners who were claiming or had claimed Incapacity Benefit in the past and thus, had some knowledge of the benefit prior to claiming. One man, who considered himself as 'early retired', experienced a sudden health change that led to a spell in hospital. Whilst he was an in-patient his wife was advised by a neighbour about the possibility of claiming Incapacity Benefit.

Other than these few examples linked to claiming Incapacity Benefit, the role of family and friends was described by the research participants as largely supportive in different ways. For example, where they were able to, they sometimes helped out with financial difficulties and provided emotional support and care (this could range from coping with frustrations about making slow progress in terms of health to coming to terms with very serious and near fatal conditions). Instances of practical support ranged from telephoning daily to make sure they were not feeling too 'down', or organising rotas to provide practical support for those just out of hospital and with a degree of immobility. Those who lacked such support or who lived some distance from family members said that they found travelling difficult. Many had the same worries as those coming to Incapacity Benefit from work discussed in Chapter 3 concerning finances and some felt guilty about relying on their partner and/or wider family.

### 4.3.4 Other routes onto Incapacity Benefit

One man's route to Incapacity Benefit appeared to be unusual but highlights a mismatch between people's circumstances, their work aspirations and the benefit system that is potentially more widespread. In effect, the benefit system became a barrier to working rather than helping him. The man had a fluctuating health condition but wanted to work. He was in receipt of JSA and did not want to claim Incapacity Benefit but did so in order to become eligible for a local authority employment scheme. He was uncomfortable doing this but felt himself lucky that he 'knew the system' having moved between work and benefits over the course of 20 years or so due to his health condition.

## 4.4 Attachment to the labour market

People's feelings about paid work were, as we would expect, associated with their social and economic circumstances. There were, thus, differences depending on, among other things, age, health, financial situation and stages of the life course. Mirroring those coming from work to Incapacity Benefit, people in this group, whilst in different financial circumstances, all considered (relative) financial need as a reason for their Incapacity Benefit claim. Most people in this sub-sample said that they wanted to work at some point in the future.

At the time of the first research interview a few in the sample felt able to work and were actively taking steps to find work even if this was not an imminent possibility. Others wanted to work but were not engaged in any work-related activity mainly because of their ongoing health conditions. Some expressed frustration that their health (still) prevented them from finding and undertaking paid work. Others thought that they would face discrimination in their attempts to get employment – not only in relation to health conditions. For example, some women with young children thought that employers would not want to employ a woman with a young child. Others who were full-time carers for children, also mentioned that childcare would be an important consideration in their return to work.

Those who did not want to work were all men in the 60-65 age group who considered themselves as either early or semi-retired. Two of these three men felt that they would not work again because of their health (whether or not they were receiving Incapacity Benefit at the time of the first research interview) and wanted to spend their time with their partner (in some cases caring for her). One man said that he would only think about returning to the labour market in order to finance, for example, some large expenditure such as house improvements.

## 4.5 Discussion and conclusion

Having considered the route of those who come from the category 'non-work' to Incapacity Benefit, a number of comments may be made: Firstly, there is a great deal of heterogeneity in this group. This is so in terms of attachment to the labour market and stage in the life course. It was clear, however, that health, whether a condition was relatively new, longstanding or fluctuating, was a key factor in all of the claims and that this interacted with the circumstances in which people found themselves in relation to paid work. For example, some people were lone carers for their children, which in some instances compounded their barriers to the labour market. Some people had recently experienced major crises in their life (which they were still coping with) and their health conditions were partly related to these experiences. Some people had fluctuating conditions which had seen them claim Incapacity Benefit previously.

Other people in this sub-sample were at particular stages in life where securing paid work was not their only or primary concern – for example, those with very young children or those who wanted to retire. That said, others in such positions wanted to work, but stressed the importance of finding work that suited their commitments.

Many of this sub-sample were not on any kind of social security benefit prior to claiming Incapacity Benefit but had other types of 'non-work' status and were, therefore, not in contact with any statutory benefit or employment agencies prior to becoming unwell. Opportunities for policy responses around such agencies are, therefore, very limited. We also noted that some of the claims for Incapacity Benefit in this group were as the result of appealing against being taken off Incapacity Benefit at an earlier stage. Though their immediate status prior to receiving their

current spell of Incapacity Benefit was as a recipient of JSA, they are arguably very similar to the people discussed in Chapter 3 whose route onto Incapacity Benefit was from work.

Some claims in this route were associated with the structure of the wider social security system and in particular the qualifying periods for National Insurance contributions or employment conditions needed to be eligible for Incapacity Benefit itself and for Maternity Allowance. As noted earlier, some people had effectively undergone a 'waiting period' for Incapacity Benefit.

In some ways there is evidence in this chapter of health and benefit services working in a joined up way. GPs appear to alert some people to a potential eligibility to Incapacity Benefit when they routinely ask them if they require a sickness certificate. Some people then pursue this with staff in a Jobcentre Plus and a claim is made. Without the initial enquiry from a GP it is possible that some eligible claimants do not receive the appropriate benefit for them. In a mirror image of this process there was evidence of Jobcentre Plus staff advising existing recipients of JSA who report to them that they are not available for work due to ill-health that, they should seek a sickness certificate from their GP. In both these examples it is possible to conclude that the benefit and primary care services are working effectively together to ensure that people are awarded the benefit most appropriate to their current circumstances.

In this sub-group people either had prior knowledge about Incapacity Benefit from being a former claimant or first learned about the benefit after becoming unwell from GPs, Jobcentre Plus staff or family and friends. Among the latter, a picture emerges of well-established processes being set in motion when someone presents themselves as unwell either to their GP or to someone from Jobcentre Plus. As one research participant succinctly put it '*I just went with the flow basically*'.

In this sub-group of the sample we have identified several examples of people making decisions about claiming benefits and about their labour market involvement that are relevant for thinking about the balance between the rights and responsibilities of Incapacity Benefit recipients in future. These include the man who could afford not to work after being made redundant and so decided not to but who subsequently became ill and hence, eligible for Incapacity Benefit, a benefit he felt entitled to claim having contributed to the National Insurance system for over 40 years, and the man who also did not want to work but whose main reason for claiming Incapacity Benefit was to have his National Insurance contributions paid for him. Decisions such as these may not be possible for new claimants of Incapacity Benefit under the proposals in the 2006 Green Paper on welfare reform (DWP, 2006) which change the balance between rights and responsibilities by suggesting the introduction of greater conditionality as part of reformed eligibility criteria.

We turn now to the final data chapter, which considers those whose route onto Incapacity Benefit is more complex than those discussed in Chapters 3 and 4 and which we describe as flowing from 'work to non-work to Incapacity Benefit'.

## 5 Moving from work to 'non-work' to Incapacity Benefit

### 5.1 Introduction

This chapter, like the preceding one, deals with the research participants who flowed onto Incapacity Benefit from a 'non-work' category. As outlined in Chapter 4, one of the main differences within the group of people who flow from a 'non-work' category to Incapacity Benefit is that some have been in paid work more recently than others. This chapter deals with those who had (relatively speaking) recently been in work.

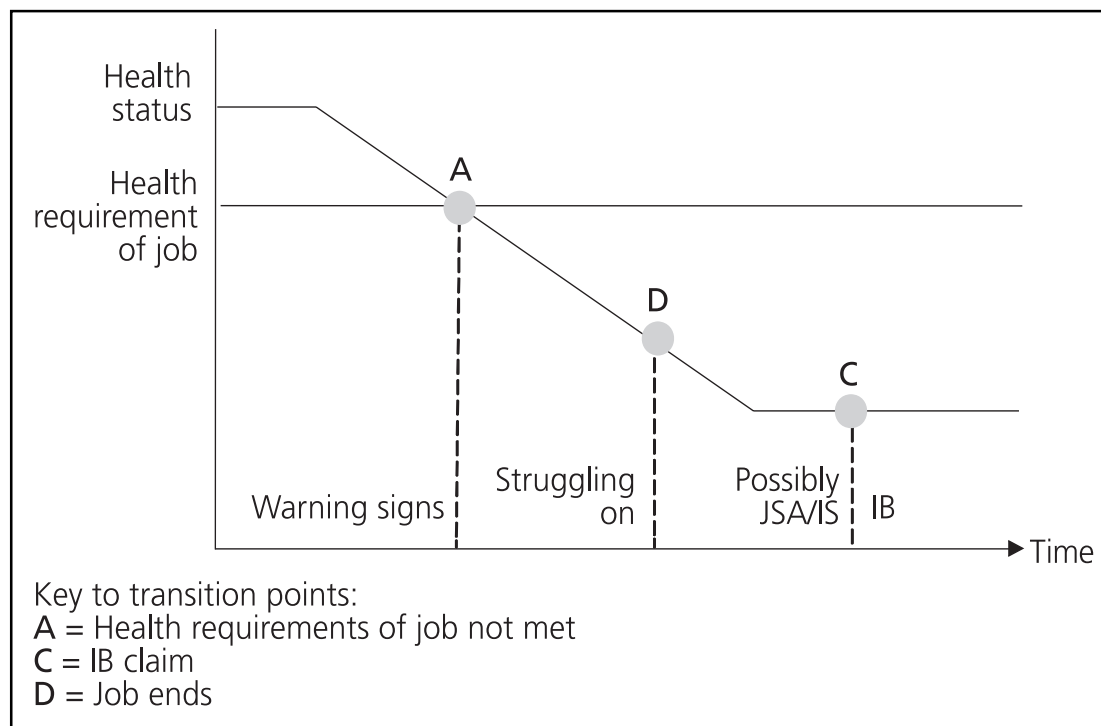
As with those who flowed from work to Incapacity Benefit (see Chapter 3), two sub-groups are identified. The first sub-group concerns those people who had left their job (for example, because of having being made redundant) and had subsequently become ill during a period when they were not in work. The second sub-group of people conversely had become ill and then lost their job after which there was a gap in time before they claimed Incapacity Benefit.

We turn first to discuss those who become ill and subsequently lose their employment.

### 5.2 Becoming ill, losing employment and the route to Incapacity Benefit

Figure 5.1 represents the phases and transition points of people losing their employment because of ill-health who subsequently experience a period out of work before claiming Incapacity Benefit.

**Figure 5.1 From work to non-work to Incapacity Benefit:  
prior health condition**



There were four people in this sub-group, one man and three women. All of the women had been signed onto Incapacity Benefit with mental ill-health and the man had a musculoskeletal condition. All of the people in this sub-group lost their employment through ill-health. None of them had access to occupational sick pay or to occupational health services. Whilst the route out of work may be similar for most people here to those coming from work in that they possibly experience a period of 'warning signs', they do not have a comparable period 'off sick'. Instead, people left their employment because they could not cope any longer, or were dismissed because of absences associated with ill-health. They then moved onto a period either claiming Jobseeker's Allowance (JSA) or not claiming anything at all for a short while before claiming Incapacity Benefit.

People in this sub-group experienced gradual changes to their health that affected their ability to do their jobs (and hence, share similarities with the people described in Chapter 3). What is different, however, is that none of the women claimed Incapacity Benefit straight away: giving them their 'non-work – Incapacity Benefit' status. In one case this was reportedly because the employer would not fill in the appropriate paperwork<sup>11</sup> and the other two people seem to have initially claimed JSA or nothing at all.

The man in this category had previously been on Statutory Sick Pay (SSP) and had lost his job when SSP ended and he was not yet well enough to return to work. He is

<sup>11</sup> The Statutory Sick Pay (SSP1) form.

situated in this sub-group, however, because he subsequently signed off Incapacity Benefit when he found work through an agency but became ill again almost immediately and so signed back on (and so is ostensibly someone who comes from the category 'non-work' to Incapacity Benefit).

### 5.2.1 The period prior to losing work

This period was characterised by taking periods of time off because of illness. Those with physical symptoms arising from mental ill-health, for example, sometimes warranted being taken into hospital, in one case, for a week of investigations. Some of the people at this stage did not know the full nature or extent of their conditions. Others had managed their condition for some time previously. Some people associated their mental ill-health with their background (some had lived for periods of time in hostels or had been in local authority care at some point). Others had recently experienced a personal crisis such as a breakdown in a relationship. One person here had a longstanding health condition-related, he thought, to his manual employment position which was (his GP suggested) exacerbated by returning to manual work before he was ready. People who had a relatively longstanding GP-patient relationship seemed to value their doctor highly.

No one in this small group left their employment on the advice of their GP. Rather, it seems that GPs were contributory to people staying in work for as long as they did.

There was some involvement from employers to help people maintain work while they were still unwell. Two employers were reported to be concerned at least initially and sent gifts and good wishes in periods of absence, for example. One employer adapted an employee's role for a short time when she came out of hospital putting her in a role where she did not have to deal with the general public. None of the people in this sub-group appeared to have a contract of employment. One person worked in temporary jobs accessed via an employment agency, and the other three worked for small, private employers. None reported having access to occupational health services.

People's employment ended in different ways. One person said that because of the nature of her illness (mental ill-health) she had reached the 'not coping' stage and had not returned to her job. She did not give her employer any notice and the employer was not reported to have followed up the absence. On taking a second sickness absence from work, one participant reported that her employer told her that since she was '*obviously going to carry on being ill*' they could not keep her on because they needed someone 'reliable' for the position. They then told her that they did not want to sack her and so would like the decision that she should leave work to (appear to) be a mutual one. In the remaining case, the employee was sent home ill from work by her employer and was later told that as she was part-time casual staff, she was not entitled to any sick pay and her job was effectively terminated.

### 5.2.2 From non-work to Incapacity Benefit

Whilst having no access to Occupational Sick Pay, the above research participants did not go straight on to claim Incapacity Benefit. Their reasons for this are not entirely clear: One person reported that when her employer did not complete the necessary benefit forms she lived off her savings before eventually claiming Incapacity Benefit. In the other two cases the research participants initially claimed JSA (though not always straight away).

Although only four people followed this route to Incapacity Benefit, the roles of GPs during the time they had a 'non-work' status before claiming Incapacity Benefit, were similar to those identified in Chapter 4 for those who had had a relatively long period in 'non-work'. GPs were either responsive to their patient's request for a sickness certificate, or more proactive in advising people to make a claim for Incapacity Benefit. Three people here had had previous periods of claiming sickness or Incapacity Benefits and requested certificates when they felt they needed them. The other person, in contrast, had not claimed before and reported being given clear instructions by her GP about what to do and where to go in order to claim Incapacity Benefit.

The contact that people had with Jobcentre Plus staff in this group was principally to process their benefit claim. None said that the staff had had an influential role in the decision to claim Incapacity Benefit. One participant had been told by someone in Jobcentre Plus to telephone if she wanted to go back to work (the participant had not perceived this as a Work Focused Interview). Another reported that Jobcentre Plus staff had told her that she could not claim Incapacity Benefit without her employer having filled in the appropriate form.

### 5.2.3 Attachment to the labour market

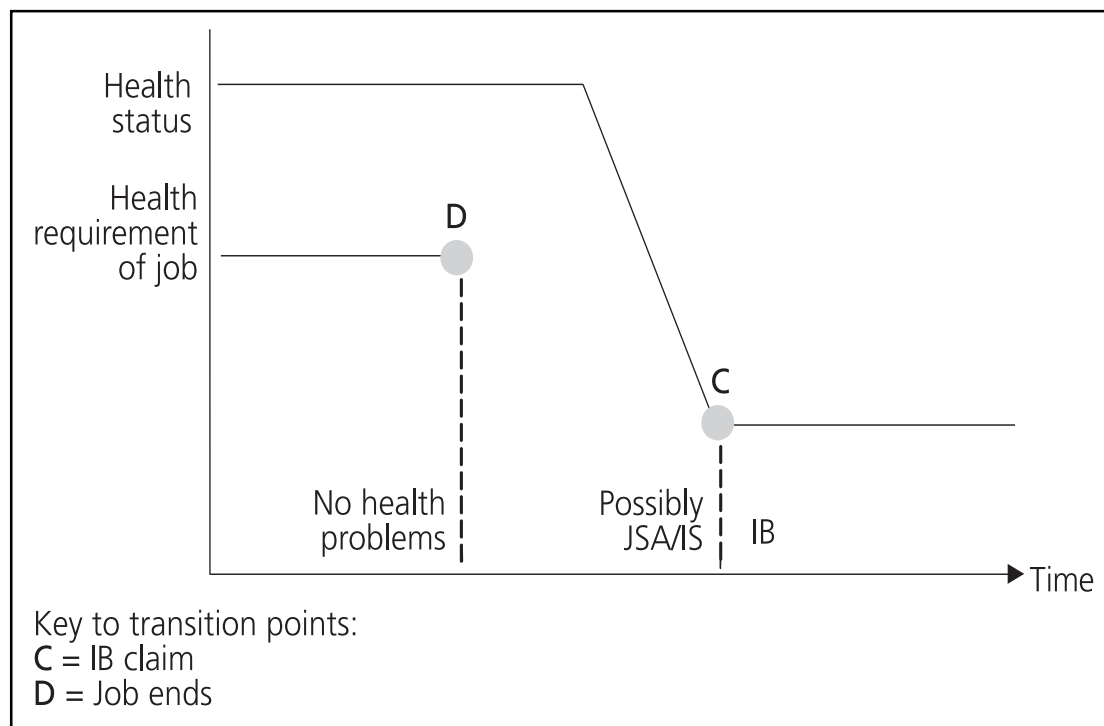
All of the people in this sub-group reported that they wanted to work, but some felt unwell enough to do so at the time of the qualitative interview (one, for example, felt unable to deal with large gatherings of people and also felt extremely tired on the medication that she was on). All of the research participants stressed that they needed to work for financial reasons because they found it extremely difficult to manage on the low amount of benefit they received, and two of them said that they felt that they might be (financially) pressured into finding a job before they felt well enough to do so. One participant thought that this pressure effectively prompted a vicious circle of becoming ill/losing jobs/claiming benefit. She also felt that her lack of skills meant that she was unable to get a 'good job' and would have ideally liked to return to full-time education but felt that she did not have the financial backing to enable her to do this. Childcare responsibilities and lack of affordable child care facilities were also mentioned as a barrier by one other participant.

We turn now to consider the route of those who first lost their employment and then became ill.

### 5.3 Losing employment, becoming ill and the route to Incapacity Benefit

Figure 5.2 represents the phases and transition points of people moving from employment to being out of work who subsequently develop a health condition.

**Figure 5.2 From work to non-work to Incapacity Benefit: subsequent health condition**



There were four people in this category, all of whom were men. The health conditions associated with the Incapacity Benefit claim were mental ill-health (including stress and depression) and cardiovascular conditions. Three out of the four claims in this sub-group followed sudden changes in health (including a heart attack, an acute mental health problem, and the diagnosis of a serious condition following a routine blood test). The occupations of people in this group included skilled and unskilled: warehouse operatives and managers, a photographer and a former educational worker.

Three of the research participants were in receipt of JSA prior to claiming Incapacity Benefit. One man had taken an early redundancy package with the intention of starting up his own business. He had claimed JSA in order to take advantage of a mortgage insurance policy he had which paid out in cases of redundancy. Another man was in the final stages of finishing a six-week course and could not afford his rent. One man was made redundant involuntarily. The other participant was not claiming any benefit and had recently been 'laid off' for a factory holiday period as a casual worker. Two reported that they had received redundancy money and the one who was laid off, was effectively on unpaid 'stand by' via an agency for more work when it became available.



Because these people had (mostly sudden conditions and had) already lost their jobs **before** they became ill, the off sick and Incapacity Benefit transition were effectively one and the same.

### 5.3.1 The transition to Incapacity Benefit

As said, the majority of people's conditions in this sub-group were sudden in nature and so the key actors' roles we highlight below are those concerned with moving onto Incapacity Benefit.

In three of the four cases above, people approached their GP for a sickness certificate. One participant on JSA who was looking for work and attending interviews, had asked his GP for a sickness certificate when he felt uncertain about how imminent medical tests would affect his ability to continue looking for work. Another man who was receiving counselling for depression, asked his GP for a sickness certificate because he did not yet feel ready to work but felt pressured into going for interviews by JSA staff. He was also finishing a short course he had paid for himself and wanted to finish it so that he could start his own business. There is some suggestion here that the decision to claim Incapacity Benefit in both these cases was a reaction to the (unwelcome) requirements of JSA rather than a major change in people's health or other circumstances.

It is also worth noting that some people's progress towards recovery (which potentially would bring them closer to re-engaging with the labour market) appeared to be impeded by lack of appropriate medical treatment. One person thought he had been given advice from his GP that precipitated a heart condition; and another had thought counselling would have helped him but had not been offered the opportunity.

No one in this group identified Jobcentre Plus staff as being influential in the decision to claim Incapacity Benefit but in discussing in the initial research interviews, some respondents did comment on contact with Jobcentre Plus. One man said that when he claimed Incapacity Benefit after receiving JSA, no one discussed the possibility of work with him. Another man who had applied for an emergency Social Fund loan but had been turned down, was left feeling angry.

There was no evidence among this sub-group of family and friends having an input in the route onto Incapacity Benefit. However, it was not always clear that all of the research participants had what they would have termed as close family at the time of their claim. Whilst some of the people here reported that their immediate family was supportive, there were also some family tensions in the periods before and after health conditions or the circumstances leading up to them appeared. Some people had not told their family that they were off work because of ill-health because they did not want them to worry.

### 5.3.2 Attachment to the labour market

This small sub-group seemed to have a strong attachment to the labour market in a similar way to the people discussed in Chapter 3 whose route to Incapacity Benefit was preceded by a recent period of employment.

All of the people in this sub-group wanted to work for a range of reasons, including financial need, for a sense of purpose and for their self-esteem. Two had already found jobs and were working at the time of the first research interview (one of these was preparing to start up a business and saw his job as temporary). Of the remaining two, one also wanted to go self-employed and the other felt just about well enough to start looking for work.

## 5.4 Discussion and conclusion

In this chapter we have identified a group of Incapacity Benefit claimants who had relatively more complex routes to Incapacity Benefit than the people we identified as coming to Incapacity Benefit 'from work' (Chapter 3) or from 'non-work' (Chapter 4) though they share similarities with both. On the one hand they **have** recently been in work but they have had some other status ('non-work') prior to their Incapacity Benefit claim. Unlike some people whose experiences are discussed in Chapter 3 however, those in this group had no opportunity of occupational sick pay, or of taking steps to retain their employment during a period 'off sick' because they had either already lost it when they became ill or they subsequently lost their employment upon becoming ill.

Although the sub-group of people who had lost their jobs as a result of being unwell was very small, it was noticeable that the three people who had mental health conditions all worked for small employers, and although there had been some efforts to accommodate reduced capabilities these had not prevented the job ending. It could be suggested, therefore, that this outcome might have been avoided if either the employer or employee had had access to help and advice about how best to manage mental health conditions in the workplace.

This sub-group has highlighted the way that some people experience the social security system as inflexible and not responsive to their own particular circumstances. As explained in Section 5.3.1, one man felt that he wanted, temporarily, to cease job seeking activity while undergoing medical tests and another found the conditionality of JSA unhelpful in his moves towards working. This suggests that the interaction between JSA and Incapacity Benefit can create barriers to working for people who are actually already positively motivated to work.

There was no evidence among this sub-group that people were in any sense 'pushed' towards Incapacity Benefit by health professionals, family and friends or Jobcentre Plus staff. Rather, as in Chapter 4 we have seen how Jobcentre Plus staff can act in what could be termed a 'claimant-centred' way by providing people with advice about what benefits might be appropriate for them when they become sick.

The last three chapters have presented findings from the initial face-to-face research interviews on people’s routes to Incapacity Benefit. The next chapter moves on to present findings from the follow-up telephone interviews carried out six to seven months later.

## 6 Routes off Incapacity Benefit

### 6.1 Introduction

This chapter reports findings on the labour market position of the study sample in October 2005, six or seven months after the initial research interview. This part of the study was largely exploratory and not intended to generate in-depth qualitative data comparable to the earlier face-to-face interviews. The main aim of the follow-up interviews was to identify where people had left Incapacity Benefit and whether their route off was related in any way to their route on.

Data collection was conducted by telephone using a standardised instrument (see Appendix C). Follow-up questioning to explore responses in more depth was not attempted.

As explained in the introductory chapter it was possible to recontact 54 people from the original sample of 60. Their labour market positions at the time of the second interviews were:

- 11 people were in paid employment and no longer receiving Incapacity Benefit;
- seven people were not in receipt of Incapacity Benefit, but not in work. Four were receiving a different social security benefit, and three had effectively left the benefit system;
- six people had, at some point, ceased to receive Incapacity Benefit but had subsequently returned to the benefit;
- 30 people were still on the same claim for Incapacity Benefit.

## 6.2 The route from Incapacity Benefit to paid work

As mentioned already, at the time of the follow-up interviews, 11 people (of the 54 contacted) had taken up, and were still in, paid employment. One person had only started work a few weeks before the interview, but most had been working for between two and eight months. Seven people had returned to their old employer, two had started new jobs and two had become self-employed. There was a wide range of types of employment, including professional, skilled and manual jobs. It was noticeable that all but one of the 11 people in this sub-group had taken on or returned to full-time jobs. The one part-time worker was working for 28 hours a week. The income reported was mostly in the low and middle range (from around the minimum wage to up to £25,000 per annum).<sup>12</sup>

### 6.2.1 The role of health changes

The 11 people in the sample who had left Incapacity Benefit for paid employment all still reported having health conditions for which they were receiving ongoing treatment. The health conditions covered musculoskeletal conditions, mental health problems, and cardiovascular and other conditions. One man reported his condition had stabilised rather than improved or deteriorated, but most (nine) reported an improvement in their health of whom, seven said that this had contributed to their return to work. There were two interesting exceptions, however: One person had found a new job, connected to her usual profession, but commensurate with her reduced capabilities. In contrast, a man with a musculoskeletal condition reported that his health had worsened but that his financial need to work had led him to return to work although he had not disclosed his condition to his employer.

Six people had experienced what we have defined as a gradual change in health, two had had more sudden changes and three had lost their jobs at the same time of going off sick but had returned to work since. One person who went off sick suddenly, had suffered a broken leg and the other had experienced an acute illness that was subsequently treated, though not cured. Noticeably, none of the 14 people in the study whose route to Incapacity Benefit we have categorised as from 'non-work'<sup>13</sup> (described in Chapter 4) was in paid work at the time of the follow-up interview, although one had returned to work but had left shortly afterwards (because the job clashed with childcare responsibilities rather than for health reasons).

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<sup>12</sup> The exception here was a self-employed professional whose income was based on an hourly rate of £50.

<sup>13</sup> Two people in this category could not be contacted for a follow-up interview.

### 6.2.2 Influences on the return to work

In the initial research interviews all 11 people had expressed positive motivations to return to work. These were usually expressed as the need to work for financial reasons, but some were also motivated by the social and emotional benefits of work that they missed while on Incapacity Benefit. Despite the emphasis on the financial need to work, none of the people reported in the follow-up interview that they were in receipt of tax credits, although one person had applied for, and was awaiting, a decision. From the data provided it is possible that one of the sample might have been earning too much to qualify (see footnote 9). One person receiving the minimum wage commented that the tax credit forms were too hard to complete and he had not submitted an application.

In the follow-up interviews, people who were in paid employment were asked what factors had been important in helping them make the transition back to work. As mentioned earlier improvements in health were referred to by seven of the 11 in the sub-sample. Even more people mentioned health treatments and interventions as important. Interestingly, while six people said their GP was an important influence, no one mentioned other health workers, perhaps reinforcing the finding from earlier chapters that employment is not discussed very often with health professionals other than GPs. Only two people mentioned their employer as an important factor in their return to work. One gave details of how their work schedule was adjusted so that less was expected. Two other people said their employer had made some adjustment (including a special chair, and longer breaks) but did not think these were important in the transition to work. Another, noticeable finding was that no one said that Jobcentre Plus staff had been important in the move into work. (We discuss the implications of this in the concluding section of this chapter.) Similarly it was interesting that no one mentioned other organisations as having played a role. Hence, for example there were no mentions of New Deal for Disabled People (NDDP) job broker organisations or charitable or voluntary organisations.

Having returned to work, most people thought they would still be in the same job three months after the follow-up interview. The exceptions were the man who was working despite no improvement in his health who was uncertain how long he would be able to continue, and the man whose work came via an employment agency and who always worked in an uncertain environment. He expected to be working in three months but probably doing something different.

It is difficult to discern any patterns in the data on people's return to work. The 11 people in the sample had a diverse range of circumstances before their claim for Incapacity Benefit and during the time they were on benefit. Some were able to return to their old employer, others had skills that could be used in a new job or self-employment, and one person occupied a place at the fringes of the job market picking up work from an employment agency. Most had also been able to access appropriate health services, including medication, physiotherapy, and surgical operations, which contributed to them being ready to return to work.

Returns to work, therefore, might be seen as being enabled by the right combination of factors. Health conditions need to reach a point at which work becomes possible again, there needs to be employment opportunities available and people must be sufficiently motivated to make the transition.

### 6.3 Other routes off Incapacity Benefit

Seven people of the 54 followed up in October 2005 were no longer in receipt of Incapacity Benefit. Four were receiving a different benefit (including Jobseeker's Allowance (JSA) and Income Support (IS)) while three were not receiving a benefit at all.

There were no identifiable patterns in the data, as might be expected from a small sub-sample. The group included men and women with a range of ages and health conditions, including musculoskeletal, cardiovascular, mental health and sensory impairment. The seven cases serve to emphasise the diversity in people's changing circumstances that lead them to leave Incapacity Benefit.

Four of the seven people here reported improvements in their health since the first research interview, while two said their health had not changed. Only one person said his health had worsened, but he was content living on his occupational pension and savings and not claiming any benefits. He also said he did not want to work again. Two women reported improvements to their health at the follow-up interview but of more relevance was the fact they were pregnant; one was being supported from a partner's income, the other was receiving IS as a lone parent. In answer to the question about where they expected to be in three months time, neither of the women expected to be back at work although both had said at the initial research interview that they wanted to work in the future (though they were not pregnant at the time).

Four people were looking for work and receiving IS or JSA or were not receiving any benefit while being supported by a partner. All four had come to Incapacity Benefit originally from a 'non-work' status, two from prior receipt of JSA and two from being students. Three thought they would be back in work in three months, but the other had experienced barriers in his efforts to find work that he attributed partly to discrimination against people with visual impairments, and did not know whether he might be in work or not.

From the limited data available it is, nonetheless, possible to suggest that for the people in this study who left incapacity benefits but not for employment, this was not necessarily experienced as a negative transition. Two were pregnant, one considered himself retired, and three expected to be back in work within three months. All viewed the short- and medium-term future positively. Furthermore the seventh member of this sub-sample was also looking for work and wanted to work even if he was less optimistic about being successful in the short- or medium-term.

## 6.4 Moving off and back onto Incapacity Benefit

Six people in the study had come off and returned to Incapacity Benefit in the time between the first and the follow-up research interviews. Five of these had had paid employment during this time. One man's route off and back onto Incapacity Benefit was different. He had come off Incapacity Benefit because the health condition that had led to his original claim had improved sufficiently for him to move to JSA but he then developed an unrelated health condition that led to a new, successful claim. In the rest of this section, therefore, data are presented from the five people who had experience of working.

Again, this was a very small sample but apart from a wide range of physical and mental health conditions, there was perhaps less diversity than in the sub-groups discussed so far. They shared several characteristics that warrant some discussion: First, all five had had recent experience of working before their initial Incapacity Benefit claim (three had come onto benefit directly from work, and two had come via the 'work/non-work/benefit' route) and expressed a strong commitment to working though some recognised that their capabilities were (at the time of the first research interview) reduced and that returning to their old jobs was unlikely, at least in the near future. Secondly, it was noticeable that three of the five people who had been in work had got their jobs through employment agencies and had had recent employment histories of low paid insecure employment. Only one person returned to their old employer. Thirdly, apart from one man in his 60s, this was a relatively young group (all in their mid-30s or younger).

All five reported that prior to returning to work they had experienced either a period of improved or stabilised health. Nevertheless, all five also cited their health as the sole or a contributory reason for them leaving their new employment. Three of these mentioned new health conditions as being relevant here. The remaining two, therefore, would appear to have taken on jobs that were not within their capabilities at the time (both of whom were working for new employers). Four of the five jobs undertaken were full-time (the part-time job was for 20 hours a week). Two people reported that they were receiving tax credits in addition to earnings.

The commitment to working expressed by all of the sub-group at the initial research interview was maintained by most at the follow-up interview. Four of the six appeared to be optimistic about returning to work and expected to be back in work within three months; another was also optimistic and expected to be back in work at some point but the timing was dependent on an operation. The only exception was a woman with multiple health conditions whose deterioration in health was perhaps the most serious and viewed her poor health as a major obstacle to returning to work in the foreseeable future.

There are some similarities between this small sub-group and the larger sub-group of people who had returned to and were still in work at the follow-up interview. They were committed to work and either were able to access employment opportunities, had a job to return to, or had transferable skills. However, some of the



group developed new, unrelated health conditions that led to them leaving their employment soon after taking it up. Two others had possibly tried to get back into work either too soon (given their health status) or into an inappropriate job beyond their capabilities.

## 6.5 Remaining on Incapacity Benefit

Thirty of the 54 Incapacity Benefit recipients with whom follow-up interviews were carried out were still in the same period of claiming six or seven months after the first research interview. This group included both men and women of diverse ages. They also had a wide range of health conditions but it is possibly noteworthy that very few had mental health conditions.

The picture of their health changes during this time contrasts starkly with that described for the people who had left Incapacity Benefit (in Sections 6.2 to 6.4). The most common experience for **those** people was of health improvements or at least stabilisation of conditions. For those still on Incapacity Benefit, however, nearly half reported that their health had worsened and nearly as many reported no change. Only five in this sub-group said their health had improved, although of these, three said that the improvement was not enough for them to consider working. One person with multiple health conditions reported both improvement and deterioration. In the follow-up interview, two questions were intended to explore whether people attributed the lack of improvement in their health to some aspect of statutory health services.<sup>14</sup> Of the 23 people who offered a response, only one mentioned being on an NHS waiting list as contributing to her lack of progress, and one mentioned poor treatment from a hospital department. The majority of the other respondents answered that the nature of their condition was the main reason for worsening or stable conditions.

One of the most striking findings from this group was the change in thoughts about working between the two research interviews: In the first interview the large majority expressed positive aspirations about working in the future, whether or not their route to Incapacity Benefit was from work or 'non-work'. The only exceptions were four men in their late 50s and early 60s who had severely limiting chronic or degenerative conditions, and a younger woman with multiple physical health problems. However, when asked in the follow-up interviews where they expected to be in a further three months time the responses were very different. (Because of the time period used for sampling at the beginning of the project, the question was effectively asking people what they expected to be happening to them after approximately a year on Incapacity Benefit.) Only three people responded that they expected to be in paid work, and one person thought he might be in voluntary work. Five people did not feel able to assess what might be happening, while the remainder chose the response 'not working'. This latter group of people were asked

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<sup>14</sup> See Appendix C, questions 31 and 32.

why they thought they would not be working, to which most replied that their health would not allow a return to work by then. Several expressed a wish to 'retire' even though they had not yet reached the state retirement age. There appeared also to be a possible age effect here. Almost all of the sub-sample aged over 50 did not expect to be working in three months time; more people who were in their 40s or younger said they would be back in paid or voluntary work, or said they did not know.

## 6.6 Discussion and conclusion

Of the 54 people followed up in October 2005 six or seven months after the first research interview and approximately nine or ten months after coming onto Incapacity Benefit, 18 were no longer receiving the benefit. If we add the six people who had come off and returned to Incapacity Benefit, the total 'off flow' during the period of the study was 24. These figures are in line with what we would expect from administrative data about off flows which show that after six months from the start of a claim, around a quarter of claimants leave Incapacity Benefit and nearly half leave within 12 months. There is nothing to suggest, therefore, that our sample was in any way unusual.

One of the principal aims in carrying out the follow-up interviews was to investigate whether there might be links between the routes by which people come on to Incapacity Benefit and their routes off. The idea was not necessarily to reach firm conclusions here but to generate possible hypotheses and lines of enquiry that could be pursued in the survey of new claimants planned for 2006 as the second stage of the study. In this concluding section, therefore, we look at such links, and offer observations on the important relation of health to what happens to Incapacity Benefit recipients, on the role of Jobcentre Plus staff, and on tax credits.

We have suggested that for many of the people who returned to work and were still in work at the follow-up interview, they had possibly benefited from the combination of improved or stabilised health conditions, a strong commitment to work and, not least, something to their advantage in labour market conditions (such as having a job to return to, transferable skills, or opportunities to access employment). The labour market position of the 14 people who were followed up from the 'non-work to Incapacity Benefit' route makes an interesting contrast. None of these were in paid work although five had left Incapacity Benefit, four of whom were looking for work. There is the suggestion in the data then that the route back to work for people coming to Incapacity Benefit from 'non-work' is likely to be more difficult or a lengthier process than those with a more recent attachment to the labour market.

By looking at the data from the 16 people in the study who had experience of working after the first research interview (11 who were still working and five who were back on Incapacity Benefit), we can see that most people returning to work experienced an improvement in their health beforehand, or had conditions that had stabilised. Twelve of these reported that improvements in their health contributed to

their return to work, ten of whom also mentioned that some form of health treatment had also contributed (the others attributed their health improvement to 'time'). It was noticeable, though not perhaps surprising, how people's accounts of either getting back to work or of staying on benefit were dominated by discussions about health. There were mentions of needing work that fitted changed capabilities, of feeling possible discrimination in looking for work, and of some employers being supportive and helpful, but these were few in comparison with the number of references to health.

It is interesting to reflect on the findings that where people had returned to work (including the 11 discussed in Section 6.2 and five in Section 6.4), no one mentioned any positive involvement of Jobcentre Plus staff. This could be an indication of the likely lack of formal contact between Incapacity Benefit claimants and Jobcentre Plus in the areas selected for the research, which excluded areas involved in the Pathways to Work pilots. People in Jobcentre Plus areas should have had at least one face-to-face interview with an adviser, but in areas yet to introduce Jobcentre Plus even this limited contact would not necessarily have taken place. It is possible, therefore, that opportunities for Jobcentre Plus to mention back-to-work help (including financial help such as tax credits) would be very limited. It is also possible that the finding that all but one person went into full-time work is a reflection of lack of Jobcentre Plus involvement. In Pathways to Work areas, for example, there is extensive contact between benefit recipients and Incapacity Benefit advisers who, where appropriate, might introduce the idea of part-time (or voluntary) work either as a stepping stone to longer hours or as a desired outcome in itself (Dickens *et al.*, 2004).

There is some policy interest in the actual and potential role that tax credits play in helping people return to work from Incapacity Benefit. Earlier, we presented the data from the follow-up interviews in which people were asked questions about their levels of income from working and whether they were, or had been, in receipt of tax credits. The data here are clearly limited (particularly, we do not know the incomes of other household members such as partners) but it was surprising that so few people were receiving a tax credit when income levels suggest that they might be eligible. If we compare the findings here with evidence about the (lack of) influence of Jobcentre Plus staff in the transition to work, it is possible to speculate that some, perhaps many, people are not aware of a possible entitlement and are not connected to potential sources of information.

The finding that the aspirations and expectations about work of people still on Incapacity Benefit at the second research interview had, for many, changed considerably (with fewer people expecting to work again in the medium-term) was striking. It is possible, therefore, that policy interventions in the earlier months of a claim would be worth considering.

In this and the preceding chapters, findings suggest that there is much to inform policy thinking about both the reform of Incapacity Benefit and welfare to work programmes that might either avoid the necessity of claiming Incapacity Benefit in the first place or assist a return to the labour market. The final chapter, therefore, summarises the main findings and addresses their possible policy implications.

## 7 Summary and conclusion

In the first part of this conclusion we summarise findings by returning to the research questions that the study was designed to address. To recap, these were to:

- provide a detailed investigation of the routes and processes by which people leave work or benefits and flow onto Incapacity Benefit;
- identify any 'transition points' at which current or future interventions may help people into work or active job seeking;
- provide greater understanding of the perceptions people have about qualifying for and receiving Incapacity Benefit;
- increase understanding of experiences of, and attitudes to, the disabled element of tax credits;
- investigate people's exits from Incapacity Benefit in relation to their routes on to the benefit.

Following this summary, we set out how these findings might help to inform policy making around social security benefits, job retention and welfare to work programmes.

### 7.1 Routes onto Incapacity Benefit

In this section we summarise findings about the different routes onto Incapacity Benefit and the transition points on those routes, and look at the roles of key actors in the process, including GPs and other health professionals, employers, family and friends, and the staff of Jobcentre Plus offices. Other important findings in relation to the structure of the social security system and people's attachment to the labour market are also summarised.

#### 7.1.1 Routes and transition points

The report initially identified two distinct routes to Incapacity Benefit, from work and from various 'non-work' statuses. These might be thought of as 'standard' routes, which form the basis of official administrative statistics that distinguish between

people on the grounds of their status before their Incapacity Benefit claim. Many of the people participating in the study were found to conform to these 'standard' routes. Their experiences were analysed in Chapters 3 and 4 respectively. However, some people had more complex routes that were characterised by a fairly speedy transition from work to 'non-work' and then onto Incapacity Benefit. Their experiences, some of which were similar to those coming to Incapacity Benefit through one of the 'standard' routes, were analysed in Chapter 5.

We have summarised the routes onto Incapacity Benefit identified in this study as follows from:

- work;
- a 'non-work' status;
- work to 'non-work' to Incapacity Benefit.

People with a 'non-work' status included those defined as economically active on Jobseeker's Allowance (JSA), and others defined as economically inactive such as those in early retirement, and in full-time education.

By definition, everyone taking part in the study had one or more health conditions that affected their ability to do paid work. For most people, some change in their health status was an integral part of the route onto Incapacity Benefit.<sup>15</sup> Again, for most people it was possible to identify either a gradual change in their physical or mental health or a sudden, unexpected change (such as an accident, or heart attack).

From early fieldwork and the review of literature about sickness, incapacity and work (reviewed in Chapter 2) we constructed a framework for analysing people's experiences. The purpose of constructing this framework was to provide a means of systematically analysing and comparing people's individual accounts of their move to Incapacity Benefit, and also to be able to identify possible points at which policy interventions might be possible (the subject of the second half of this chapter). The framework comprised the following phases, though it was clear that not everyone passed through each of these sequentially. The phases were:

- a period of deteriorating health (that we have termed the 'warning signs' phase);
- for those in work, a period of 'struggling on', when their ability to fully meet the physical or mental requirements of the job are affected;
- a period 'off sick' prior to claiming Incapacity Benefit
- a period of claiming and receiving Incapacity Benefit.

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<sup>15</sup> This was not always the case, however: For some people it was not a change in their health that was directly associated with the timing of their Incapacity Benefit but by them (eventually) meeting the National Insurance contributions conditions for the benefit.

Whether, and for how long, people experienced these different phases depended on a number of factors, including whether they followed one of the 'standard' routes or a more complex route to Incapacity Benefit, whether their health change was gradual or sudden, and whether they were eligible for either Statutory Sick Pay (SSP) or some form of Occupational Sick Pay. It is possible to hypothesize that there is a 'transition point' between each of these different phases. In practice, from the accounts of the people in this study, it is clear that the transitions to going 'off sick' and going onto Incapacity Benefit are easy to identify and mark, for example, changes in the relationship and types of contact with employers.

What also emerged from the analysis was that these transition points were, importantly, often coincidental with an initial visit to a GP or the loss of employment, highlighting the potential pivotal role played by GPs and employers in the route to Incapacity Benefit.

### **7.1.2 The roles of GPs and other health professionals**

Most people in the study had had contact with their GP at some point before going onto Incapacity Benefit (a few who had had sudden health changes had received sickness certificates from hospitals). Some people were in contact with GPs during the time their health was getting worse (in both the 'warning signs' and 'struggling on' phases) but for others, their first contact with a GP was the occasion they were given a sickness certificate and went 'off sick'. It seems that GP involvement with people whose route to Incapacity Benefit was from work was largely reactive. They tended to deal with the immediate health problems of their patients rather than engage in any activity or discussion that might be described as 'job retention'. The provision of sickness certificates for people in work, therefore, seemed to be a largely routine, unproblematic and unremarkable experience, despite the one or two people in the study who remarked that their GP seemed reluctant to issue a certificate.

For people coming to Incapacity Benefit from a 'non-work' status, we identified again a reactive, passive role in GPs who responded to requests from their patients or who asked whether or not they required a certificate. However, in a few cases the GP seemed to be more proactive and a catalyst for a claim by making clear suggestions and encouragement that a claim would be beneficial. There was some evidence here that this was more likely to occur when people presented multiple, non-health-related problems, particularly financial problems, to their GPs.

There were no examples in this study of GPs initiating discussions about a return to work when people were off sick. However, there were references to GPs being very supportive of people's efforts to get back if they themselves broached the topic. In general, the picture emerging is one of most people being positive about their GPs when they were seen as being in some way supportive (for example, in issuing sickness certificates, or arranging appropriate health care, or in supporting benefit applications and appeals).

For some people, contact with NHS services was mainly with hospital or other treatment services rather than face-to-face with GPs. From these people's accounts it appeared that discussions about work rarely took place (there were just a few examples of physiotherapists and CPNs responding to questions from patients).

### 7.1.3 The role of employers and employment relations

The people in this study reported varied experiences of how their employers responded to their health changes and problems. Several findings have emerged that are useful for thinking about policy. However, it is not appropriate to generalise about employer behaviour from this study, principally because any efforts at avoiding the necessity for sick leave were by definition ineffective (i.e. because the research participants all eventually were on Incapacity Benefit). That is not to say that efforts at **job retention** were similarly ineffective since seven of the 11 people who had returned to, and were still in, work by the time of the follow-up interview went back to their old employers.

There were a number of findings relevant to policy thinking: First, some employees do not tell their employers about worsening health, either during the 'warnings signs' phase or the period of 'struggling on'. The principal explanation offered for this by people in the study was fear of losing their job. Secondly, however, when people did inform their employers of health problems there were still difficulties. Some employers were unresponsive to requests to change work patterns or duties, but also some employees were unresponsive to employers' attempts to suggest some form of adjustment. This is interesting in that it suggests at least some willingness to make a positive response to changing health status from both parties. Thirdly, and less positively, many people in this study had lost their jobs at some point before claiming Incapacity Benefit. For some this occurred without any period of being off sick. For others their job ended after a period of SSP or Occupational Sick Pay.

Occupational health services within firms were seen by some people in the study in a positive light, when they facilitated access to treatment services or facilitated adjustments to their working arrangements. Others did not wholly trust occupational health staff who were seen as essentially holding the interests of the company over those of employees. Occupational health specialists accessed via GP surgeries, in contrast, were viewed generally positively. People working for small, private employers had no access to occupational health services through their employer, and it was among this group that there seemed to be a greater likelihood of people losing their jobs at an early stage in the Incapacity Benefit process.

### 7.1.4 Role of family and friends

Across all of the different routes to Incapacity Benefit the role played by family and friends was largely similar, although some people in the sample had no network of friends or relatives. Occasionally they were the source of information about Incapacity Benefit but mainly they acted in what was often described as a supportive

way, backing up the judgments and decisions of the research participant. For some, however, relations with family members were strained.

### **7.1.5 Role of Jobcentre Plus staff**

Jobcentre Plus staff were often reported to have advised claimants on appropriate benefits, although some people in the study experienced some kind of difficulty in getting their claim successfully processed or had negative experiences in their dealings with staff. Some people on JSA were advised to claim Incapacity Benefit when their health condition meant they could not fulfil the conditions of JSA, and those enquiring about maternity benefits were informed about Incapacity Benefit if they did not have the sufficient contributions to qualify for Maternity Allowance.

The picture presented by many people in the study was, therefore, of Jobcentre Plus staff acting in a professional manner in accordance with the current structures and procedures of the social security benefit system. There is also a case, however, for improving standards of service and administration.

## **7.2 Understanding and perceptions of Incapacity Benefit**

In this section we draw on data from across the whole study group of 60 Incapacity Benefit claimants. Understanding of Incapacity Benefit fell into three distinct groupings. Some new claimants knew very little or nothing about Incapacity Benefit prior to claiming, and others had some knowledge through family or friends who had been or were still recipients. The most knowledgeable people were those who had claimed Incapacity Benefit in the past themselves. Several sets of views emerged when people were asked in the initial research interview about their feelings about Incapacity Benefit and the experience of receiving it.

Just over half of the study group expressed views that were, if not explicitly positive in tone, at least not negative. There were two dominant sets of views among these people:

One view was couched in terms of 'rights' and 'entitlement'. Some people talked about Incapacity Benefit as an entitlement earned through contributing to the National Insurance scheme and said that they had no negative thoughts about claiming it when they could not work because of health problems. No one here, therefore, thought there was any stigma attached to claiming Incapacity Benefit. This view was held particularly by older people in the study, many of whom were new claimants who had made contributions over a lifetime of working.

Another group of people talked in terms of Incapacity Benefit being there when they 'needed' it in times of sickness, providing 'help' when they could not work. Again, these people did not express any sense of stigma or other negative associations with claiming the benefit. Some referred to being 'grateful'.



By contrast, just under half of the study sample expressed mainly negative views, sometimes very strongly. People talked about the 'stigma' of being on Incapacity Benefit and of feeling degraded. Many thought that they were viewed by others (including employers) as 'scroungers' or 'second class citizens'. There were very few actual examples of being treated in this way; people's views here were possibly more a reflection of how they felt in themselves while being on benefit. Many referred to the financial necessity of claiming, and a preference to be working and '*earning my own money*'.

There was no evidence from this study that any particular view about Incapacity Benefit or about feelings about receiving it had any effect on whether people stayed on or left the benefit. For example, among those who had been or were still in work at the time of the follow-up interview, there was a wide range of views encompassing all three of those described above. There was no indication from the data, therefore, that having negative views acted as any kind of incentive to come off Incapacity Benefit.

The wide range of views about Incapacity Benefit is interesting and raises some difficult problems for policy, particularly in the context of an imminent debate about benefit (and wider welfare) reform. We return to these later in the chapter.

### 7.3 Experiences of, and attitudes towards, tax credits

The evidence about attitudes to, and experiences of, tax credits from this study is somewhat limited. This is for two principal reasons: Firstly, most of the people in the study appeared to have little or no knowledge about tax credits. For the people whose route to Incapacity Benefit was from 'non-work' this is not perhaps surprising, particularly if they had been out of the labour market for some time. Tax credits would largely have been irrelevant to their lives at the time. In contrast, many of the people who had had recent experience of work might have been expected to have at least some knowledge, particularly those with low incomes. It is not possible, from the type of data collected in this study, to suggest the extent to which people might have been eligible for tax credits since detailed information about earnings (and importantly, the earnings of partners and other household members) was not explored.

The second reason for the limited data available is that very few people had received a tax credit in the past, and none were in receipt at the time of the follow-up interview. Where people had received it, views were positive. One possible reason for the relative lack of knowledge of tax credits among this study group might be that many were unlikely to be connected to the sorts of networks where such information would be given to them. Because the study was located outside Pathways to Work Pilot areas, the contact with Jobcentre Plus staff by the research participants was limited, and, as mentioned in Chapter 6, no one appeared to have contact with a job broker or other advice agencies.

## 7.4 Routes off Incapacity Benefit

The analysis presented in Chapter 6 about people's routes off Incapacity Benefit is primarily based on data from the follow-up telephone interviews carried out in October 2005 some six to seven months after the first research interview, which was in effect around nine or ten months after the start of their period of claiming.

It was found that 11 people of the 54 contacted had gone back to work and were still in work at the time of the interview. Five other people had also had jobs in the period between the interviews but were back on Incapacity Benefit. Seven other people were no longer on Incapacity Benefit but had moved on to either JSA or IS, or were not in receipt of any benefits at all.

It was striking that all of the people who had worked or who were still working had been in recent employment. In other words, they came via the 'work' route (described in Chapter 3) or the 'work to 'non-work' to Incapacity Benefit' route (covered in Chapter 5). None of the people in the study who came via the 'non-work' route (Chapter 4) had had any work, although some had moved on to economically active benefits. Three types of transition into work were identified: People returned to their old employer, had transferable skills that they used in new employment (including self-employed jobs), or went back to short-term, low paid jobs at the lower end of the labour market (often obtained through employment agencies). Nearly all of the people who had worked (14 of the 16) were in full-time jobs. No one was receiving tax credits, though one person was awaiting the outcome of an application.

Improvements in health, or sometimes stabilised health conditions, were mentioned as important factors in the return to work by most people here. Support from GPs and family and friends was also important for some, but no one mentioned Jobcentre Plus staff as having an important role.

Thirty of the 54 people followed up had remained on Incapacity Benefit throughout the study period. A striking finding was the change in people's expectations and aspirations about working that had occurred in the time between the research interviews. While most had initially expressed positive views about working again, they were generally far less optimistic at the follow-up interview; only three of the 30 expected to be back in work within three months. Some, all in their late 50s and early 60s, had decided that, in contrast to their earlier view, they did want to work again. Most attributed this to their health (either deteriorations, onset of new conditions, or conditions that had not improved). Many of these had chronic or degenerative conditions. Few among this group had mental health conditions.

## 7.5 Discussion of policy implications

As mentioned in Chapter 1, there has been considerable policy interest and concern about the growing Incapacity Benefit population. Much of the policy innovation

since 1997 has been aimed at helping people who are on long-term sickness and disability benefits move towards and into work, and more recently in job retention for people off sick from work. The latter can be seen as a preventive policy aimed at avoiding the need for people to claim Incapacity Benefit (and hence, from becoming long-term recipients).

This study has been aimed at further informing preventive approaches by exploring the factors involved in people's routes onto Incapacity Benefit, not only for those in work but also for those coming from other 'non-work' routes. In this final section we look at how the findings from the study can inform policy making in the overlapping areas of health, employment and social security, recognising that these are not mutually exclusive areas of policy, and making reference to policy documents from Department for Work and Pensions (DWP), Department of Health, and the Health and Safety Commission over the past two years or so.

We have noted throughout this report how the issue of health dominated most people's accounts of their route on and either their route off or their continued receipt of Incapacity Benefit. The main questions arising for policy from this finding are (a) can the onset or deterioration of health problems be avoided, (b) if they cannot then what can be done to prevent health conditions leading to a period of sickness, and (c) what can be done when people are off sick to avoid the need to claim Incapacity Benefit?

The response to the first of these questions certainly appears to lie outside the area of social security policy. However, prevention of health problems and the promotion of good health are already being addressed in a number of ways concerning lifestyles, the environment and employment. Of relevance here are government initiatives on healthy living and healthy workplaces, for example, in the White Paper *Choosing Health* (Department of Health, 2004), the Health and Safety Commission's 'Strategy for workplace health and safety' (HSC, 2004, 2005) and the more recent cross-departmental policy document on *Health, work and well-being* (DWP, Department of Health, HSC, 2005).

The potential for more employer involvement and for occupational health services is suggested by the findings from this study. Healthy working practices and safe and healthy environments, including the avoidance of stress (including that caused by workplace bullying) could act as very early preventive measures that might halt an eventual route onto Incapacity Benefit. Proposals for an increase in occupational health services for employers (for example, in DWP *et al.*, 2005) can therefore be seen as a helpful policy response here.

Of course, not all health conditions can be avoided or prevented. When they occur therefore the objective becomes, where appropriate and if at all possible, to help people to continue working in some way that does not contribute to further worsening of their health condition. From this study it does appear that opportunities for, for example, adjustments to work duties or reduced hours, did not arise or were inappropriate or unacceptable. Again, it is possible to see that access to occupational

health advice and services for employers and employees (of the type proposed in, among other places, DWP *et al.*, 2005) have the potential to help people stay in work.

Many people in this study spent time on health service waiting lists for consultations, investigations and treatment. Clearly, for them, access to speedy and appropriate health interventions had the obvious potential to help them hopefully return to work before a claim to Incapacity Benefit becomes necessary. Harnessing appropriate health resources is outside the control of many people, but there is clearly a role for GPs, other health professionals and also occupational health services in identifying and mobilising what resources are needed.

The finding that the aspirations and expectations about work of people still on Incapacity Benefit at the second research interview had changed (with fewer people expecting to work again in the medium term) suggests that more effective policy interventions in the earlier months of a claim would be useful.

So far the policy implications discussed are relevant mostly for those people whose route to Incapacity Benefit starts with them in work (including those who then go on to a short period of 'non-work') whether they experience the phases of 'warning signs' and 'struggling on' in connection with a gradual change in health, or experience a sudden change where it might be linked in some way to their work. By contrast, any possibilities for preventing people who have a 'non-work' status from eventually moving on to Incapacity Benefit would appear to be very restricted and limited to health care that, for some, might maintain them as job seekers.

We have noted that the period in which people are 'off sick' from work can vary enormously in length. However, based on the evidence of those people who returned to work during the study period, it is important for some form of contact to be maintained between employer and employee after they do go off sick, whether or not SSP or Occupational Sick Pay arrangements are in place. Some people, for example, still have contracts of employment even after commencing Incapacity Benefit. The chances of ending a period on Incapacity Benefit appear to be much greater for those with a job to return to (or whose employment is at the lower end of the labour market where movement in and out of temporary, insecure work is more the norm). Although the focus of this study was not on the detail of how people got back to work after a period of being off sick, it is possible to suggest that any measure or arrangements that help maintain contact between employer and employee would be valuable. Included here might be formal sickness management policies and procedures (properly implemented) and, again, access to occupational health services.

We have also seen that for many people, their engagement with health services coincides with going off sick. Some people's routes to Incapacity Benefit might be avoided therefore, and their return to work expedited, if they received timely and appropriate health care and interventions. The waiting lists for NHS consultations, operations and treatment were found to militate against a speedy recovery and/or

return to work for a lot of people in the sample. Waits often extended to months before people saw hospital doctors, had investigations such as MRI scans, or started courses to treatment. Some people experienced successive waits, for example, a wait for consultation and diagnosis followed by a further wait for treatment. In some cases, the more time people had to spend waiting for treatment, the more likely they were to lose their employment.

There is an additional negative effect of having ill-health for extended periods. Many people in the study reported negative psychological effects of being unwell combined with being away from work (during which time they can become worried about their job and about their finances, and experience feelings of boredom, frustration and isolation). Some people eventually required treatment for depression and anxiety. The effect of this, in many cases, is that people became further distanced from the labour market making a return to work further away and more difficult to negotiate later.

Before turning attention to the policy implications for Jobcentre Plus staff, it is worth reflecting on the question of whether GPs could have a greater role in avoiding the move onto Incapacity Benefit. We have identified what we have described as a reactive role that GPs perform (in responding to requests for sickness certificates or offering them seemingly routinely to working age patients) and a slightly more proactive role in advising people (often those with problems in addition to their health) to claim and facilitating their claim. Very rarely did GPs and people in this study discuss work beyond if and when they should stop work. It is possible to suggest, therefore, that an initial consultation with a GP is not the optimum time to be talking about returning to work.<sup>16</sup> Furthermore, at this stage many people are still in contact with their employers and time off work is, at least initially, not likely to be contentious. Whether there could be a greater role for GPs here is difficult to argue. There were certainly no suggestions from the people in this study that GPs could be doing anything more in relation to their employment at this stage. Indeed, on the whole, people in this study did not consider it the role of the GP to initiate discussions about work. Their concerns were more with getting access promptly to investigative and treatment services.

It is difficult from this study to identify ways in which Jobcentre Plus staff could act in more preventive ways. In this study we found examples of Jobcentre Plus processing benefit claims when people presented themselves already having received a sickness certificate for a GP, and examples of claimants of JSA being advised to claim Incapacity Benefit when they could not meet the job search requirements of that

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<sup>16</sup> It is interesting to compare this input from GPs with that of Jobcentre Plus staff. One of the findings from the initial introduction of Jobcentre Plus was that Work Focused Interviews for people claiming sickness benefits were too early. At the point of claiming, people were not well placed to be thinking about returning to work. This finding informed the timing of Work Focused Interviews in the Pathways to Work pilots, which commence after eight weeks of claiming.

benefit due to ill-health. It is possible to conclude from this that the way in which Jobcentre Plus staff acted here was consistent with good practice within the current structure of out-of-work benefits. While assisting with benefit claims and advising on appropriate benefits might be considered proper practice, it is difficult to see how there could be arguments in favour of them advising any of the people in this study **not** to claim Incapacity Benefit.

Finally, there are implications from this study for the reform of Incapacity Benefit, currently the subject of a Green Paper not published at the time of writing. At this stage, therefore, we will limit discussion to some of the findings that might inform later debate: First, there was no evidence from this study that Incapacity Benefit was in any sense acting as an incentive to people to claim Incapacity Benefit. Most people's routes to benefit started with health problems and for many, the experience from that point was in a sense 'automatic' as well-established procedures of sickness certification, sick pay arrangements, and claiming Incapacity Benefit went into action.

Secondly, there was evidence of people's circumstances, including their National Insurance record, influencing the time at which a claim for Incapacity Benefit could be made (i.e. unrelated to changes in their health at the time), affecting whether or not they were eligible for Maternity Allowance, or affecting eligibility for some employment schemes. We see here evidence of a mismatch between elements of benefit and employment policies that could hinder eventual moves towards work that could be addressed in the context of reforming Incapacity Benefit.

To conclude this report we should recall that this qualitative study was intended partly to produce findings to inform social security, employment and health policy. However, it was also designed to inform the development of a quantitative survey planned for later in 2006. Many of the findings have been necessarily tentative or raised as hypotheses, therefore. However, the opportunity to pursue them further should generate findings that are generalisable to the wider Incapacity Benefit population and which can further inform policy.



# Appendix A

## Research design and methods

### A.1 Recruiting the study group

The study group for the project comprised 60 people who had begun a new period of claiming Incapacity Benefit in January 2005.

Initially three fieldwork sites were selected, using two sets of data:

- administrative data on the percentage of the working age population in receipt of either Incapacity Benefit or Severe Disability Allowance in May 2004. These data are given for local authority areas only;
- Incapacity Benefit flow data for November 2004. These are given for Jobcentre Plus districts.

The aim was to identify Jobcentre Plus Districts whose constituent local authority areas reflected low, average and high rates of Incapacity Benefit recipients. Incapacity Benefit rates are defined as the percentage of the working age population in receipt of Incapacity Benefits. A 'low' rate was defined as three to four per cent; 'medium' as six to eight per cent, and 'high' as over ten per cent. Local authority areas within the catchment areas of the Pathways to Work pilots were excluded from selection.

The selected Jobcentre Plus districts were Cambridgeshire (low Incapacity Benefit rate), Cheshire (medium) and South Yorkshire (high). The table sets out the Incapacity Benefit rates for the relevant local authorities.

A database of new recipients for these areas was supplied by the Department for Work and Pensions (DWP) but the expected numbers of claimants in Cambridgeshire and Cheshire was less than considered sensible in order to achieve the target number of interviews. Two further areas were then selected to augment the sample size. Leicestershire was selected as a 'low' Incapacity Benefit rate area to supplement Cambridgeshire, and Edinburgh as a 'medium' area to supplement Cheshire.



Letters explaining the study and inviting people to participate were sent out in February and March 2005. Letters asked recipients to reply within two weeks using a prepared reply slip and prepaid envelope if they did not want to take part in the study.

**Table A.1    Contacts with the study group**

	Number
Invitation letters sent	266
Opt-outs	64
First interviews achieved	60

This was a higher than normal opt-out rate for this type of study involving social security recipients. At the time of recruiting, however, there was a wave of press coverage about Incapacity Benefit that was largely negative in tone, often portraying Incapacity Benefit recipients as workshy or scroungers. In declining to take part, some people, particularly those with whom contact was made by telephone, referred to this adverse publicity. It is possible, therefore, that other people were also put off taking part in this way.

After the deadline for the opt-out period, potential interviewees were selected to achieve diversity of relevant characteristics and circumstances. The main aim was to include men and women who had a range of ages and health conditions. We also aimed to achieve diversity in household circumstances, economic circumstances, educational backgrounds and benefit histories.

Researchers made contact by phone with potential participants and those who had already indicated their desire to participate and explained the study further, answered any questions and asked people to participate in the initial and the follow-up interview. Appointments for the initial face-to-face interview were arranged at a time and place convenient for those who agreed to take part. All chose to be interviewed at home. Letters confirming the date, time and place of the interview were sent to participants prior to the interview.

The characteristics of the achieved sample are set out in Table A.2.

**Table A.2 Characteristics of the achieved sample**

	Total
<b>Gender</b>	
Male	35
Female	25
<b>Age</b>	
18-29	10
30-49	23
50+	27
<b>Health condition<sup>1</sup></b>	
Mental health	13
Cardiovascular	10
Musculoskeletal	23
Other	12
<b>Economic circumstances prior to claim<sup>2</sup></b>	
Paid employment	32
Other economically active	11
Economically inactive	14
<b>Qualifications<sup>3</sup></b>	
Some	36
None	22
<b>Benefit history<sup>4</sup></b>	
New claimants	38
Repeat claimants	21
<b>Household circumstances<sup>5</sup></b>	
Adults living alone	15
Adults living with other adults	44

**Notes:**

<sup>1</sup> The health conditions of two people were not known.

<sup>2</sup> Economic circumstances were not always clear and often subject to recent change.

<sup>3</sup> Qualifications ranged from NVQ level to higher degree. There were no data for two people.

<sup>4</sup> Information was unclear for one respondent.

<sup>5</sup> It was difficult to identify and recruit adults living alone. One person not included in the table was living in communal housing.

The sample selected by DWP was intended to exclude self-employed people because it was felt that, although they might have different experiences that would be of interest, we would not be able to include sufficient numbers in a small qualitative sample to be able to draw any inferences about them in the analysis. However, when interviews were carried out, two people were found to be in self-employment at the time. They have not been excluded from the analysis, however.

## A.2 Conducting the initial research interviews

Initial face-to-face qualitative interviews were used to gather data on people's current circumstances with regard to health, work, finances and household, and on the following relevant aspects of their route onto Incapacity Benefit:

- work history;
- circumstances leading to their claim (including health, financial situation, role of employers, GPs/medical professionals, family/friends, Jobcentre Plus staff);
- perceived transition points on the route to Incapacity Benefit;
- perceptions, views and attitudes about Incapacity Benefit;
- expectations and aspirations about the future, particularly in relation to work.

A topic guide was used to facilitate the interviews (reproduced as Appendix B).

Interviews lasted mostly between 60 and 75 minutes and all gave their consent to be tape-recorded. Participants received £20 as a token of thanks. Some respondents invited family members to attend the research interviews. They made additional contributions to the interviews that were included in the analysis. In three cases difficulties with recording equipment were experienced. Full notes of the interviews were made as soon as possible after the interview.

## A.3 Follow-up telephone interviews

Letters were sent to all 60 research participants in October 2005 to invite them to take part in a second interview by telephone. The purpose of the interview was to gather data about their current circumstances, details of any work undertaken, factors that had helped them return to work, and views about their future labour market participation. A structured research instrument was designed to collect the data (reproduced as Appendix C).

Contact was re-established with 54 of the original study group. One person requested a hard copy of the research instrument, which she completed and returned by post. All other interviews were conducted as planned by telephone and typically lasted between 10 and 15 minutes. A final gift of £10 was sent to the participating members after the interview.

## A.4 Data analysis

The tape-recordings from the face-to-face interviews were transcribed for qualitative analysis. Data from the telephone interviews were extracted directly from the research instruments. The data was analysed systematically and transparently, building on the *Framework* method originally developed by the National Centre for Social Research, such that display of data from the two waves of research would enable both 'snapshot' pictures and a longitudinal perspective.

# Appendix B

## First claimant interview: topic guide

FINAL DRAFT

**Routes onto Incapacity Benefits**

**First claimant interview: Topic Guide**

The aims of the first wave of interviews are to:

- Investigate routes by which people leave work or benefits and flow onto IB.
- Identify any 'transition points' at which current or future interventions may help people into work or active job seeking.
- Provide greater understanding of the perceptions people have about qualifying for and receiving IB.
- Increase understanding of experiences of, and attitudes to, the disabled element of tax credits.

### **Interviewer's introduction**

Introduce self and remind about SPRU being independent organisation.

Remind that research funded by the Department for Work and Pensions to provide information about peoples' routes onto Incapacity Benefit.

Explain the issues to be covered:

- Work history.
- Circumstances leading to their claim (including health, financial situation, role of employers, GPs/medical professionals, family/friends, Jobcentre Plus staff).
- Perceived transition points.
- Perception of Incapacity Benefit.
- Expectations and aspirations.

Interview will last around one hour or so, and will be in the form of a discussion.

Explain use of tape recorder and transcripts, confidentiality and how the material will be used. Explain discussion will have no effect on any benefits or dealing with Jobcentre Plus, DWP, etc. Answer any questions or concerns.

Check informed consent.

Give money gift.

## **TOPICS**

1. Background.
2. Work/claim history.
3. Route onto Incapacity Benefit:
  - o Health and capabilities
  - o Financial situation
  - o Employers
  - o GPs (and other health professionals)
  - o Household members/friends
  - o Jobcentre Plus staff
4. Transition points.
5. Perceptions of Incapacity Benefit.
6. Expectations and aspirations.

## 1. CLIENT CHARACTERISTICS

Can I begin by asking some general information about you and your personal circumstances?

- Age
- Household members/partners circumstances
- Caring responsibilities
- Tenure (including length)

## 2. WORK/CLAIM HISTORY

- When did you make your most recent claim?
- What were you doing when you made your claim for IB?

*PROBE: whether or not they still have a contract of employment, were unemployed, looking for work, claiming other benefits, etc.*

- What kind of work have you done in the past?

*PROBE: employment history, periods of sick leave, incapacity, unemployment.*

- What kind of training or qualifications do you have?

*PROBE: how their educational background/qualifications/ training links with the type of work they have undertaken.*

- Have you ever previously claimed IB? If so, when and for how long? Why did you move off IB on that/those occasion/s?
- Do you know if it is a Jobcentre Plus office that you claimed at? Have you had a Work Focused Interview?

## 3. ROUTE ONTO INCAPACITY BENEFIT

**INTERVIEWER NOTE:** People who are/were employed may still have been in work at that stage, or on a company sick pay scheme. Equally, the relevant time period (e.g. re. onset of illness) may extend further back. This question leads into the 'modules'. The respondent is likely to talk about their illness/condition, but note that their current ill-health may have been triggered by circumstances linked with work, their personal life or finances. For example, stress at work or home etc can trigger conditions which they otherwise manage successfully.

- Can I ask you to think back about six months (Aug/Sept time)? What were you doing then?

*PROBE: employment/benefit status.*

- Can we talk about what was happening during this time; what was changing?

## FOLLOW UP MODULES:

**INTERVIEWER NOTE:** Focus discussion on appropriate period leading up to claim, i.e. last six months or longer.

## HEALTH & CAPABILITY CHANGES

- You mentioned your health conditions. If it's ok with you, can I ask a few questions about this?

*PROBE: fully for history of the condition: whether it is a recent illness, a progressive/degenerative/fluctuating condition, gradual or sudden onset etc, linked with other periods of ill-health, or work-related.*

*PROBE: relevant changes in period leading up to IB claim.*

*PROBE: to establish which conditions affect their capacity to work, any other, possibly secondary conditions, including depression.*

## FINANCIAL SITUATION

- Has there been any kind of change in your financial situation during this time that is relevant to your recent claim for Incapacity Benefit?

*PROBE: Income - including work-related sick pay or SSP; benefits (JSA, IS, HB, CTB, DLA others); other household members finances. Income protection or other insurance.*

*PROBE: Expenditure, especially sickness or disability-related.*

I'd now like to ask you some questions about other people that you might have had contact with during this period.

## EMPLOYERS

If previously or still employed at the time they became incapacitated:

- When you went off sick, how did your employer react? Was your employer sympathetic of your situation?

*PROBE: to see whether supportive.*

*PROBE: to see whether they believe stigma is attached to particular conditions, for example, back problems, mental health.*

- Had you mentioned to your employer that you had a health problem before you went off sick? If yes, what was their response?

*PROBE: whether employer tried to accommodate their needs at time of becoming incapacitated that would allow them to stay in work.*

- Has your employer/colleagues kept in touch with you while you have been off work?

*PROBE: has this been helpful? Would they have liked more contact? Has contact from employers been seen as a positive thing?*

*PROBE: who made contact, e.g. Occupational Health. Offers of workplace adjustments, change in hours, area of work etc?*

*PROBE: person's perception of contact as welfare-based with a view to ensuring that they do not become isolated/alienated from workplace, or if it has involved pressure.*

If a long-term condition:

- In previous spells of employment has employer been responsive to your health condition and your needs associated with it?

*PROBE: to see whether sympathetic or supportive.*

*PROBE: to see whether they believe stigma is attached to particular conditions, for example, back problems, mental health.*

## **GPs (AND OTHER HEALTH PROFESSIONALS)**

- You have/have not mentioned your GP. What was their role during this time, if any?

*PROBE: Have you discussed work with your GP? Who raised work – was it you or the GP?*

*PROBE AS APPROPRIATE: What did you want to discuss with GP? Did you want advice about working; what did GP say? What did you think of their response?*

*If GP raised work – what did they say? Were they encouraging you to think about work OR saying that you should not work? What did you think of this? Did you expect them to discuss work?*

*How have your dealings with GP affected how you think about yourself and work?*

*What was the GP like in the lead up to the claim? Has GP been supportive/proactive with the claim?*

*PROBE: Have GPs made referrals to other services, e.g. counsellors, physiotherapists, specialists etc. If so, what kind of input has been received from other health/social service professionals? What did they think of it?*



## HOUSEHOLD MEMBERS/FRIENDS

- How have family and friends responded to you being unable to work through your illness?

*PROBE: have family/friends influenced the way they view sickness and relation to work? Have they had views about the respondent stopping work? How has household been affected by their health condition? Have there been any changes in the status of others in the household – e.g. benefit, work, caring?*

*PROBE: to see if family/friends have offered/assisted in helping them to maintain social contact, morale, confidence etc.*

*PROBE: to see if family/friends are supportive re. any thoughts about returning to work.*

## JOBCENTRE PLUS STAFF

- Have you had any contact with Jobcentre Plus staff during this time?

*PROBE: to see Jobcentre Plus staff gave any advice re. moving onto Incapacity Benefit.*

*PROBE: for any involvement in possible job retention, including discussions re. NDDP, tax credits etc.*

*PROBE FULLY REFERENCES TO TAX CREDITS: knowledge, views.*

## 4. TRANSITION POINTS

- Thinking about how you came to be on Incapacity Benefit, do you think there were any **key** things that led to your claim? Is there anything in your story that you would say was a key factor?

*PROBE: was there a defining factor, or was their route onto Incapacity Benefit a combination of personal, work, financial, health etc. related factors?*

## 5. PERCEPTIONS OF IB

- People have different views about claiming IB. How did you feel about making a claim for IB? Do you see this as positive/helpful, or as a backward move? Did moving onto IB feel permanent or temporary?

*PROBE: is claiming a constructive process (e.g. providing an income, contributing to return to labour market), or negative (e.g. a cycle which will be difficult to get out of, as carrying social stigma.)*

- When you went to your local Jobcentre/Plus office, did you go there specifically with a view to making a claim for Incapacity Benefit, or did you go along not really knowing what benefit you were eligible for?

*PROBE: how did they know what to do/where to go – GP, word of mouth, previous experience etc?*

- Do you feel that claiming Incapacity Benefit was something you chose to do, or do you feel that the decision was out of your hands?

*PROBE: as to whether they did so out of financial necessity – only possible source of income; if directed by GP, JC+ etc; own choice; progression from SSP or other benefit.*

- Do you know about the Personal Capability Assessment?

*PROBE: what do they know about the process, what happens and what it is for. Do they see it as a hurdle or a threat? Is it a source of worry/concern?*

- Have you had a medical examination in connection with your claim?

*PROBE: whether or not they attended a medical examination, reasons for non-attendance, experience of examination.*

I'm now going to ask you some questions about your thoughts about the next six months.

## 6. EXPECTATIONS AND ASPIRATIONS

- If we now move on to thinking about the future, how important would you say it is for you to be able to work?

*PROBE: how important employment is to them, their commitment to re/entering the labour market and their reasons.*

- In what way does your illness/condition affect your capacity to work at the moment?
- How do you think a return to work would affect your health?

*PROBE: for reasons behind positive/negative/neutral answers PROBE (if negative response): If GP/family/others suggested working could be positive for your health, what would you think?*

- Is your condition one that you expect to change to allow you to return to work?
- What do you think are the biggest obstacles to you being able to work?

*PROBE/PROMPT: for example: age, poor health, local labour market conditions, lack of qualifications, concerns about mobility, pain, stress, stigma of 'sickness', reduction in income through loss of associated benefits, low self-esteem?*

- What kind of help, support, information or advice would you find useful in helping to overcome some of the concerns that you might have about finding and keeping a job, OR sustaining your job?

*PROBE: regarding what measures could be taken to counter concerns about returning to work and facilitate re/entry into the labour market.*

*PROBE: to see if anyone – e.g. employers, JC+ staff, medical professionals, Occ Health, CAB have discussed options with them. For example, change in hours/conditions, NDDP/JBs, WORKSTEP, Access to Work, Tax credits etc.*

- Is there anything else you would like to add at all?

Thank respondent and remind them that we'll look forward to contacting them again in the autumn.

Check phone contact details.



# Appendix C

## Questionnaire for follow-up telephone interviews

## Routes onto IB: Outcome Questionnaire

Introduce self/SPRU.

Explain that we are interested in hearing about what has happened to them since we last spoke with them about their experiences of claiming IB nearer the start of the year. We would like to know how and why their situation has changed, or not, as the case may be.

Explain that this is different to the in-depth interview that they took part in earlier in the year. Today, we would mostly like to ask them a series of 'Yes/No' questions with room for expansion on certain points and we aim to keep them no longer than 10 minutes or so.

Explain that their answers will remain anonymous.

Reassure them of the independence of SPRU.

Explain that they will be posted out gift of £10.

Participant ID number

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**SECTION 1: BACKGROUND INFORMATION**

First of all, before we ask you some questions about how your situation may or may not have changed since the last time we spoke with you, it would be helpful if we could just check some basic background information with you?

1. **Gender**                      Male ☐                      Female ☐

2. **Age**

3. **Highest educational/professional qualification held**

CSE/GCSE

☐

O Level

☐

A Level/Highers

☐

NC/HNC/HND/NVQ/City&Guilds

☐

Degree

☐

Higher Degree

☐

Other

☐

.....

.....

4. **Household composition – are you:**

Sole occupant

☐

Sharing with others

☐

Living with partner

☐

Sole adult living with children

☐

Living with partner and children

☐

Other

☐

.....

.....

5. Tenure

Owner/occupier	<input type="checkbox"/>
Private rented	<input type="checkbox"/>
Local authority/housing association rented	<input type="checkbox"/>
Other	<input type="checkbox"/> .....
.....	

Thanks very much, moving on now, we would like to get a snapshot of your situation at the moment. When we last spoke with you then you were off sick because of ..... *(Researcher to restate how participant came to be on initial claim for IB – e.g. off work with stress; fractured tibia. This gives immediate context, and so lessens possibility of causing offence in following questions).*

So if we could just update your situation at the moment then:

SECTION 2: CURRENT LABOUR MARKET POSITION

6. Which of the following best describes your situation at the moment?  
Please tick as many of the following as you feel apply.

Working	<input type="checkbox"/>
Looking for work	<input type="checkbox"/>
Off sick	<input type="checkbox"/>
Unemployed	<input type="checkbox"/>
Retired	<input type="checkbox"/>
Studying	<input type="checkbox"/>
Carer	<input type="checkbox"/>
Other (specify)	<input type="checkbox"/> .....
.....	

Participant ID number

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**7. Can I just check, are you in paid work at the moment?**Yes ☐ go to question 10No ☐ go to question 8**8. Have you done ANY paid work since we last spoke with you?**Yes ☐ go to question 9No ☐ go to question 25**9. Thinking about the FIRST job you had since we last spoke with you, what was the main reason for that job ending?**a) asked to leave/sacked ☐b) mutual agreement between self and employer ☐c) left because of health ☐d) the job was temporary/finished ☐e) other (please specify) ☐ .....

.....

**10. Job title** .....**11. Were/are you**Employed ☐Self-employed ☐**12. When did you start this job?** -- / -- / -- --**13. Do/did you work**Full-time ☐Part-time ☐



14. How many hours per week do/did you work?

15. How much do/did you get paid?

per hour

per week

per month

per year

16. Are/were you in receipt of any in work benefits/support, e.g. tax credits?

.....

.....

.....

.....

.....

.....

17. Is/was this your only form of paid employment in the period since we last spoke with you?

Yes ☐ go to question 19

No ☐ go to question 18

Participant ID number

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**18. How many jobs have you had since we last spoke with you?**

**19. In the FIRST job Were/are you working with the employer you went off sick from (when we last spoke to you)?**

Yes ☐

No ☐

**20. Were/are you doing the same type of job/role (with new employer if applicable)?**

Yes ☐

No ☐

**21. Thinking back to your return to work, did your employer offer to alter your role or workplace environment to make the transition back to work easier for you?**

Yes ☐ go to question 22

No ☐ go to question 23

**22. In what ways was this done?**

Hours ☐

Different role ☐

Short/long term workplace adaptations (specify) ☐ .....

.....

Other .....

23. Thinking about your return to work, we’ve found a number of things that have been important for other people in helping them get back to work after a period of sickness absence. Could I ask you to rate the following things in terms of whether they were ‘not important, quite important or very important’ in your return to work?

	Not Important	Quite important	Very important
a) Improvement in your health	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) Getting relevant health treatment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) Help and support from your GP	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) Help and support from other health workers (specify) .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) Jobcentre Plus staff (specify) .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f) Other advice workers (eg CAB, trade unions) (specify) .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g) Family and friends	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h) Original employer (support from; changing hours, duties)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i) Other	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
.....			

Any one factor most important? .....

.....

24. Which of the following options best describes the time you’ve spent in paid work since the last time we spoke with you?

All of the time☐ (specify months) .....

Most of the time☐ (specify months) .....

Some of the time☐ (specify months) .....

Participant ID number

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**25. Have you done any voluntary work since we last spoke with you?**

Yes ☐ go to question 26

No ☐ go to question 27

**26. How much voluntary work do you/did you do?**

Number of hours per week?

**27. Are you in receipt of any social security benefits or tax credits?**

Yes ☐ go to question 28

No ☐ go to question 29

**28. Specify (tick as many as appropriate):**

JSA

☐

IB

☐

IB Credit only

☐

IS with a disability premium

☐

IS without a disability premium

☐

DLA

☐

Tax credits

☐

Other

☐

.....

.....

SECTION 3: CHANGES IN CIRCUMSTANCES

Thanks very much, moving on now, we would like to get a brief idea of how your circumstances might have changed for you since the last time we spoke

29. Firstly your health. Overall would you say that your health situation has:

- Improved☐ go to question 30
- Got worse☐ go to question 31
- Has not changed☐ go to question 32
- Other .....
- .....

30. What reasons would you give for the improvement in your health?

- Time☐
- Treatment (specify) ☐ .....
- .....
- Other .....
- .....

Go to question 33

31. What reasons would you give for the decline in your health?

- Insufficient treatment☐
- Nature of condition☐
- NHS waiting list☐
- New health condition(s) (specify) ☐ .....
- .....
- Other .....
- .....

Participant ID number

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**Go to question 33****32. What reasons would you give for your health condition staying the same?**

Related to nature of condition

☐

Treatment has stabilised condition

☐

No treatment available

☐

NHS waiting lists

☐

Other .....

.....

**33. Thinking back to when we last spoke with you, have there been any significant changes in your personal/ household circumstances?**

No significant changes

☐

Anyone joined the household

☐

Left the household

☐

Gained qualifications

☐

Gone on a training course

☐

Moved home

☐Change in household income ☐ (specify).....

.....

Other .....

.....

**Thinking back, what has happened since we last spoke with you 6 months or so ago in terms of social security benefits? Have you:**

**34. Made a claim for any benefit?** Yes ☐ No ☐  
Specify.....

**35. Been awarded benefit** Yes ☐ No ☐  
Specify.....

**36. Been refused benefit** Yes ☐ No ☐  
Specify.....

**37. Had benefit stopped/disallowed?** Yes ☐ No ☐  
Specify.....

### **Future employment**

**38. In terms of work, where do you see yourself in 3 months time?**

Still employed (in current job)	<input type="checkbox"/> end interview
Back to work	<input type="checkbox"/> go to question 39
Not working	<input type="checkbox"/> go to question 40
Different employment	<input type="checkbox"/> end interview
Voluntary work	<input type="checkbox"/> end interview
Other .....	
.....	

Participant ID number

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**39. What do you currently consider to be the main things preventing you from working at the moment?**

Health

☐

Lack of treatment

☐

Lack of suitable jobs

☐

Other .....

.....

**End of interview****40. Why do you think work is not feasible for you in the near future?**

Health

☐

Lack of treatment

☐

Lack of suitable jobs

☐

Other .....

.....

**End of questionnaire****Thanks for taking the time to speak with me and best wishes for future**





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